

Pathways Project: Development of a Multimodal Innovation To Improve Kidney Supportive Care in Dialysis Centers

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Abstract

Current care models for older patients with kidney failure in the United States do not incorporate supportive care approaches. The absence of supportive care contributes to poor symptom management and unwanted forms of care at the end of life. Using an Institute for Healthcare Improvement Collaborative Model for Achieving Breakthrough Improvement, we conducted a focused literature review, interviewed implementation experts, and convened a technical expert panel to distill existing evidence into an evidence-based supportive care change package. The change package consists of 14 best-practice recommendations for the care of patients seriously ill with kidney failure, emphasizing three key practices: systematic identification of patients who are seriously ill, goals-of-care conversations with identified patients, and care options to respond to patient wishes. Implementation will be supported through a collaborative consisting of three intensive learning sessions, monthly learning and collaboration calls, site data feedback, and quality-improvement technical assistance. To evaluate the change package's implementation and effectiveness, we designed a mixed-methods hybrid study involving the following: (1) effectiveness evaluation (including patient outcomes and staff perception of the effectiveness of the implementation of the change package); (2) quality-improvement monitoring via monthly tracking of a suite of quality-improvement indicators tied to the change package; and (3) implementation evaluation conducted by the external evaluator using mixed methods to assess implementation of the collaborative processes. Ten dialysis centers across the country, treating approximately 1550 patients, will participate. This article describes the process informing the intervention design, components of the intervention, evaluation design and measurements, and preliminary feasibility assessments.

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Introduction

Current care of older patients with advanced CKD in the United States is not patient centered, nor does it incorporate a supportive care approach to optimize patients' quality of life. The absence of this approach is a major deficit in care (1). Patients >75 years are the fastest-growing segment of the dialysis population. If they are also frail or sick with multiple comorbid conditions, these patients may not experience a survival benefit from dialysis and are thus candidates for a primary supportive care and often a specialty palliative care approach (2). Further, although these patients often experience a significantly shortened life expectancy, planning for end-of-life care is limited, resulting in higher rates of use of the intensive care unit and in-hospital deaths at the end of life compared

with patients with other chronic illnesses (3). Patients likely receive such high-intensity care because their decline is not planned for through sensitive goals-of-care discussions and advance care planning processes. Despite advances in other countries (notably Australia, Great Britain, and Canada), progress on providing patient-centered kidney supportive care has lagged in the United States (4). This article describes development of an intervention to foster uptake of supportive care best practices for patients receiving dialysis.

Intervention Development

The Pathways intervention is a multicomponent intervention structured after the collaborative-learning approach of the Institute for Healthcare Improvement

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(IHI) Breakthrough Collaborative Model (5). We based the selection of the Breakthrough Collaborative Model on the quality-improvement experience of Quality Insights Renal Network 5. Learning collaboratives are an increasingly accepted tool used to speed diffusion, implementation, and innovation of care models (6,7). The IHI Collaborative Model for Achieving Breakthrough Improvement is one systematic, time-limited (12–18 months), tested, format for a collaborative (8). The premise of a Breakthrough Collaborative is that all participant teams teach (sharing knowledge, information, and data) and, through this process, all participants learn, share what they have learned, and repeat the cycle until the spread and adoption of knowledge and improvement is applied to multiple settings. Collaborative participants also learn from, and are coached by, expert faculty in focused topic areas of the “change package” best practices. Another feature of the Breakthrough Collaborative is use of the IHI Model for Improvement, in which teams test a series of small changes using multiple small-scale Plan-Do-Study-Act cycles. In this way, teams incrementally adapt the recommended changes outlined in the change package to their own organizational context. Authors B.V. and D.E.L. attended the IHI Breakthrough Series College in March 2017 to gain a background in conducting a collaborative. In addition, an IHI consultant was retained to advise on development of the change package.

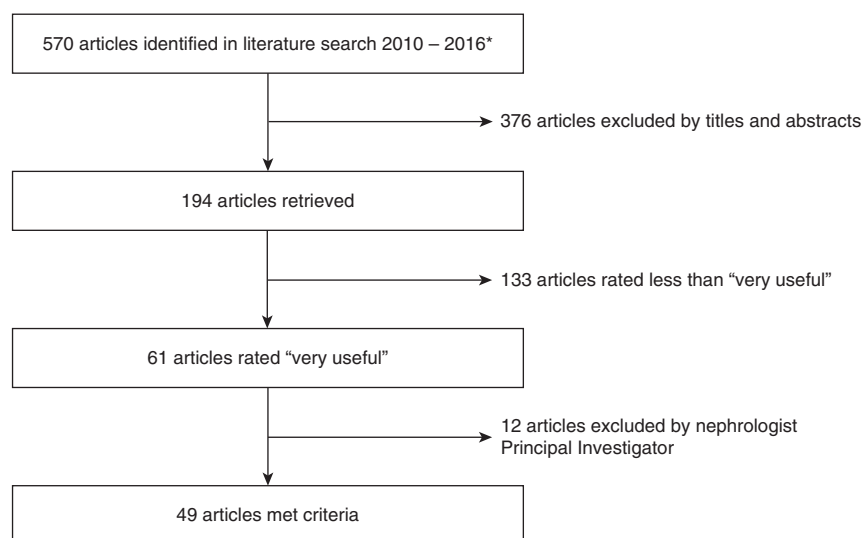
Development of the Change Package

A change package is a set of evidence-based practices to be implemented with quality-improvement methods, and it is a central component of a Breakthrough Collaborative (9,10). To develop the Pathways change package, we followed three steps: (1) conducted a systematic literature review, (2) interviewed implementation leaders and subject-

matter experts to identify key considerations in the implementation of supportive care programs, and (3) convened a technical expert panel (TEP) to distill information gathered in the first two steps and prioritize change concepts.

First, we conducted a focused literature review on interventions and outcomes in supportive care for patients with CKD and kidney failure (Supplemental Material 1 for search terms and strategy). The review was intended to add to comprehensive literature reviews conducted on literature from 2000 to 2009 for the US clinical practice guideline development (11), and from 2010 to 2014 for the international Kidney Disease Improving Global Outcomes Controversies Conference in Supportive Care Project and subsequent published executive summary (12). Therefore, searches were limited to publications in PubMed written in English from January 1, 2010 to January 17, 2017 on adults only.

Pathways Project investigators (D.E.L. and A.H.M.) also identified articles of interest through a hand search. After duplicate references were discarded, 570 abstracts and titles were reviewed for possible inclusion (Figure 1). A total of 193 full-text articles were then retrieved and data were abstracted from each article using a concise online electronic coding form to capture information about the intervention features (*e.g.*, disease focus, setting of care), study elements (*e.g.*, design, sample size, population, outcomes assessed), and key outcomes/findings. Twenty professional members of the Coalition for Supportive Care of Kidney Patients volunteered to review the abstracts and rate their usefulness. All raters had substantial clinical or research expertise in supportive kidney care. Raters summarized key findings of the article relevant to delivery of supportive care, and rated the article’s usefulness for “developing a pathway for conservative management, providing supportive care through the continuum of kidney disease, or discontinuing



* Search criteria: PubMed, adults, English literature, dates of publication January 1, 2010 through December 31, 2016, and population including chronic kidney disease, end-stage renal disease, and dialysis patients.

Figure 1. | Flow diagram of article selection process for development of the change package. Of 570 articles initially identified, 49 articles met criteria for inclusion.

dialysis.” A total of 61 articles were rated “very useful.” These were reviewed by one investigator (A.H.M.) for final inclusion on the basis of relevance and usefulness in developing a change package.

A list of “pearls” potentially leading to change concepts was compiled from 49 of the 61 very useful articles (Table 1). These were grouped into three conceptual areas: (1) nondialytic management, (2) supportive care throughout the continuum of care, and (3) dialysis withdrawal. When articles were similar in nature, one was selected for inclusion to reduce the burden on the TEP. The systematic literature review was supplemented by a gray literature review to identify tools, measures, and implementation information not covered in the peer-reviewed literature.

Pathways investigator D.E.L. interviewed 17 nephrology and palliative care implementation leaders who had implemented some element of kidney supportive care in English-speaking countries (see Supplemental Material 2 for interview guide). The interviews addressed critical success factors for establishing a supportive care program and overcoming implementation barriers. Five core components needed to create a system of supportive care emerged from these interviews: (1) appropriate patient identification; (2) communication about advance care planning, and goals of care conversations; (3) symptom assessment and management; (4) collaboration with palliative care specialists; and (5) early referral to community resources, such as hospice

Table 1. Concepts extracted from literature search and provided to technical expert panel for building change package

Pearl That May Lead to a Change Concept

Pathway 1: conservative, nondialytic management

Need hospice referral early; increase in symptoms in last 2 mo

Patients receiving conservative, nondialytic management may live longer than a year and need to be treated with primary palliative care skills

Geriatric syndromes (including frailty), old age, and high comorbidities predict poor prognosis with dialysis; may not be a survival benefit with dialysis

Caregivers of patients receiving conservative, nondialytic management need psychosocial support for such patients to do well

Quality of life and patient experience better for patients receiving conservative, nondialytic management than for patients receiving dialysis, but survival is shorter; patients willing to trade-off survival for better quality of life

About 15% of patients choose conservative, nondialytic management; patients respond well to choice of conservative, nondialytic management when pathway is established and presented as “natural aging” or “holistic care”

Erythropoietin-stimulating agents decrease fatigue of patients receiving conservative, nondialytic management

Risk algorithms for patients with high 90-d mortality after starting dialysis can be used to inform decision about initiating dialysis

A total of 93 patients over age 80 with 1- and 5-yr survivals on dialysis comparable with the population of patients with kidney failure as a whole; need to examine reasons why

Pathway 2: supportive care throughout the continuum of care

Need someone to “own” symptom assessment who knows how to treat them

Summary of overall palliative care approach

Referral to nephrologist/palliative care clinician before 3 mo allows time for consideration of all RRT options, including conservative, nondialytic management; preemptive transplant; and home dialysis

Patients with CKD perceive end-of-life care practices of dialysis centers as falling short of their many needs; areas of unmet need include advance care planning, pain and symptom management, and psychosocial and spiritual support; need to “normalize” advance care planning discussions earlier in dialysis patient care

Need a communication framework for dialysis decisions that identifies patients’ values and goals and results in treatments being aligned with them

Frequent outpatient palliative-care clinic visits leads to fewer emergency-department visits and hospitalizations

Conceptualize care in all three pathways as patient centered rather than disease oriented

A need for all three pathways; patients and families do not understand palliative care and hospice

Screen for depression early and often

Sharing Patient’s Illness Representations to Increase Trust (SPIRIT) is an effective advance care planning intervention to prepare caregivers for decisions and improve bereavement; caregivers have a limited understanding of patients’ values and goals

My Kidneys, My Choice is a decision aid to help patients with kidney failure with shared decision making about dialysis options

Patients want family members present and for nephrologists to be involved in the advance care planning discussions, and for their desire to participate to be determined before starting

A registry of all patients with advanced CKD who were appropriate for supportive care helped to identify what supportive care practices were being provided to patients and how often

Pathway 3: dialysis withdrawal

Tracking quality of life longitudinally can identify patients who are reconsidering whether dialysis was still worth the life it was providing

Need for improved detection of patients who are at high risk of dying; those with loss of independence; clinical deterioration; loss of function; inability to engage in meaningful, enjoyable activities; and those “dying on dialysis” using the surprise question, the integrated prognostic model, or the Renal Epidemiology Information Network prognostic score so that palliative care interventions, including advance care planning, can be offered to them

Develop advance care plan for patients at high risk of dying, including Physician or Provider Order for Life-Sustaining Treatment form, which has been shown to increase out-of-hospital death and hospice admission

Ethics committee deliberation on 111 patients who were being considered for withdrawal over an 8-yr period; patients were identified by new, severe, comorbid conditions, such as a stroke, intractable pain, or hemodynamic instability on dialysis

Nine advance care planning interventions have been studied in patients with kidney failure; one demonstrated improved patient and family well being and anxiety; others noted the importance of instilling patient confidence that their advance directives will be enacted and discussing decisions about (dis)continuing dialysis therapy separately from “aggressive” life-sustaining treatments (e.g., ventilation)

(4). These elements were presented to the TEP to consider for inclusion in the change package.

We convened a 15-member, multidisciplinary TEP consisting of patient subject matter experts (SMEs) and professionals in the areas of nephrology, healthcare policy, palliative care, hospice, and ESKD Seamless Care Organizations. There were representatives from nephrology academic programs, large dialysis organizations, nephrology nursing, hospice and palliative care organizations, and an observer from the Centers for Medicare and Medicaid Services. The disciplines of medicine, nursing, social work, chaplaincy, and healthcare administration were represented. The two patient SMEs had personal experience living with kidney failure. The TEP was sent a summary of the focused literature and the gray literature reviews before meeting, along with several key articles. The TEP met in person for 2 days in April 2017, guided by an experienced facilitator from the IHI.

The TEP was asked to evaluate and recommend best practices to include in each supportive care pathway in the change package. To develop this, the TEP discussed deficits in kidney supportive care and then developed a vision for the ideal state of goal-concordant care for patients seriously ill with kidney failure (Supplemental Material 3). They defined the ideal system as one in which patient values, preferences, and goals are elicited and respected; patients receive care that aligns with what matters most to them; and patients and families receive support, resources, and assistance to help them prepare for the end of life. They then considered the summary of evidence to develop recommendations for what evidence-based best practices would help achieve that ideal state.

After the in-person meeting, the change package was iteratively revised with TEP feedback. During this process, we paid careful attention to the use of consistent terminology that could be understood by patients and other stakeholders. For instance, on the recommendation of the patient SMEs, we agreed to use the term “medical management without dialysis” rather than “conservative care.”

The final change package consists of 14 evidence-based best practice recommendations (Supplemental Material 4, change package summary) grouped into four “change concepts”: (1) supportive care capacity (create the system); (2) values guide care (elicit and respect patient values and preferences); (3) just right care (provide the right care to the right person at the right time); and (4) throughout the continuum (bring enhanced support at the end of life). In the full change package, each best practice is concisely described using the following content: purpose, evidence, improvement process, challenges and strategies to surmount them, resources and tools, and key references (<http://go.gwu.edu/pathwaysprojectchangepackage>). The goal of each best-practice recommendation is to provide actionable evidence, rationale, and steps to guide improvement in that area.

Recognizing that the entire change package of 14 best practices would be overwhelming for centers to implement at one time, we prioritized three. Their selection was determined on the basis of input from the TEP, the findings from the literature reviews, and input from the organizational leaders of the participating dialysis organizations. The best practices selected were as follows: identification

of patient who is seriously ill, shared decision making and advance care planning, and palliative dialysis or a systematic dialysis withdrawal process for appropriate patients. Dialysis-organization leaders were strongly in favor of concentrating on patients who were seriously ill, rather than attempting to reach all patients in the dialysis center. Prioritizing patients who were seriously ill provided a tactical solution to overcoming the barrier of lack of clinician time to implement supportive care practices or engage in advance care planning. Furthermore, some TEP members expressed reservations about discussing end-of-life issues with patients who were healthier who were intent on adapting well to dialysis and/or were hoping to receive a transplant. Although all patients can benefit from sensitive discussions of goals of care, the dialysis-organization representatives on the TEP felt that starting with patients who were seriously ill would face less resistance from clinicians.

Additional Intervention Components

The classic Breakthrough Collaborative contains a number of components in addition to the change package: learning sessions, action periods, quality-improvement processes, and data collection for formative evaluation (13). We followed this schema in designing the Pathways learning collaborative (Table 2). The Pathways collaborative includes three in-person “learning sessions” of 2 days each, which are intended for “change teams” of up to five people from each participating site. In the months between learning sessions, deemed “action periods,” sites will work on implementing the best practices introduced at the learning session. During action periods, teams are expected to engage with one another through the use of multiple supports that promote shared learning; collect and submit monthly data; review monthly feedback reports; attend Pathways Project webinars and conference calls facilitated by faculty experts; and perform iterative tests of the change package recommendations *via* the Plan-Do-Study-Act approach, which asks three fundamental questions: What are we trying to accomplish? How will we know that a change is an improvement? What change can we make that will result in improvement?

The curriculum for the three learning sessions covers (1) Pathways best practices, with emphasis on the three required practices; (2) communication skills for conducting goals-of-care conversations; and (3) quality improvement and implementation (Table 3). On the basis of recommendations from the TEP, the curriculum places a heavy emphasis on improving communication skills. Before designing the Pathways curriculum, we piloted a communication module taught by VitalTalk faculty with a subset of the Pathways dialysis center teams. This led us to collaborate with the Veterans Affairs (VA) National Center for Ethics in Health Care to further adapt communication-skills training to nephrology-specific situations on the basis of the VA’s Goals of Care Conversations Skills Training for Clinicians (medical doctors, advanced practice registered nurses, and physician assistants), which is, in turn, based on VitalTalk (14,15). The nephrology-specific communication materials are now available at <https://www.ethics.va.gov/goalsof-caretraining/RenalTeams.asp>. The curriculum for the first learning session includes 7 hours of communication training delivered by VA faculty trainers. Reinforcement of

Table 2. Elements of the Pathways intervention determined on the basis of Institute for Healthcare Improvement Collaborative Model for Achieving Breakthrough Improvement

Intervention Element	Description	Purpose
Start-up		
Change package (Supplemental Material 2)	Set of 14 evidence-based best practices developed through literature review and input of technical expert panel, guiding improvement efforts designed to improve kidney supportive care and to achieve goal-concordant care, especially at the end of life.	Provide written guidance as to what to do, how to do it, and why
Change team and charter	Designated team from each participating dialysis center or CKD clinic that has agreed to work toward improvement of supportive care at their site. Each team develops a charter that specifies their goals, objectives, and plans. Teams needed to have at least one nephrologist “champion.” Other disciplines participated on the basis of site and personal preference and included social workers, nurse practitioners, administrators, patient advocates, and palliative care physicians.	Clearly identify who is going to lead change at clinical site and foster agreement on change team about their plans
Expert faculty	Interdisciplinary experts in supportive kidney care serve as faculty. Disciplines include nephrology, palliative medicine, social work, nursing, dialysis center administration, quality improvement, public health, and patient expertise.	Teach and mentor content and skills needed to implement kidney supportive care
Resource-rich intranet website and listserv	Website accessible to Pathways participants where all resources introduced during learning sessions or activity periods are housed for reference by teams. Also includes YouTube channel with videos produced by Pathways team and listserv for use by all Pathways participants.	Foster ongoing communication between teams and with faculty; promote easy access to information and tools that teams may need for implementation of supportive care
Learning sessions during collaborative		
Learning sessions	Three in-person, 2-d mini conferences where teams gather to learn content, practice skills, share learning, and plan improvement activities. Each learning session has a mix of didactic teaching from experts, opportunities to practice skills, and time to share innovations with other teams.	Foster sharing of innovations through the “All Teach, All Learn” approach of the collaborative; purpose is to provide both content knowledge about how to make change, and emotional support for the process of incrementally pushing change forward
Communication-skills training	Trained communication facilitators, from the Veterans Administration Goals of Care Conversations Skills Training for Clinicians program, delivered 7 h of content in learning session 1. This content is based on the VitalTalk model and was explicitly adapted to nephrology concerns and situations (14). In learning sessions 2 and 3, Pathways faculty provide additional communication-skills exercises to continue building skills with goals-of-care conversations using the Ask-Tell-Ask model.	Bolster communication skills to enable participants to increase confidence and competence in conducting goals-of-care conversations, including both shared decision making and advance care planning
Storyboard sessions	Each team prepares a poster that explains their progress, barriers, and key innovations. These are shared in a poster session at the learning session.	Foster sharing and spread of innovations; build team pride and enthusiasm for their work through presentation to peers
Activity periods between learning sessions		
Pathways action calls (monthly)	Monthly videoconference call with faculty and all change teams. Teams report on successes and frustrations. Faculty provide additional teaching, especially focused on communication skills and symptom management. Cases teams have encountered are debriefed.	Reinforce skills; exchange strategies between teams for overcoming obstacles; celebrate successes to build shared commitment to change
Quality-improvement indicator reports	Monthly reports provided to sites showing data on set of commonly collected quality indicators. Individual trend reports provided to each site showing their own trend month to month.	Helps sites benchmark and see progress of their site; monitoring quality indicators helps sites recognize areas of success and areas for improvement
Improvement-advisor monthly calls	Improvement advisor on the faculty holds call with each team separately each mo to discuss progress and plan for tests of change.	Provide technical assistance to sites on quality-improvement process using small tests of change; encourage sites to embed successful practices into standard workflows and processes

Table 2. (Continued)

Intervention Element	Description	Purpose
Site visits	Small teams of faculty (two to three faculty) visit each site for approximately half a day to meet with change team and other staff. Faculty consult with change team on their progress. Faculty model goals-of-care conversation with patient(s) and debrief with change team. All nephrologists (not just the champion[s]) are invited to lunch or dinner meeting with faculty nephrologist for talk on supportive kidney care and discussion of how this affects their practice.	Builds rapport between faculty and change team; allows faculty to better understand environment at each site; modeling goals-of care conversation in person with patient at the site helps change team to see how to move from the role plays practiced in the learning sessions to actually integrating the conversations in their work setting; meetings with other nephrologists helps the champion build support among colleagues and center leadership
Newsletter and email notices	Periodic newsletters with information, new relevant evidence, and reminders.	Keep Pathways participants up to date on latest evidence related to kidney supportive care and help them see the rich variety of resources available in this area; also builds connection and a sense of belonging to a larger mission
Faculty consultation as needed	As requested by local sites, faculty consult <i>via</i> phone or videoconference.	Provide ready access to expert consultation as needed
Customized tools and resources as needed	As sites identify areas of need, Pathways team develops additional tools or resources. For instance, a pocket card using Ask-Tell-Ask communication cues was developed after faculty observed the need for a reminder staff could keep with them on the floor (see Supplemental Material 3).	Provide targeted help as additional areas of need are identified

Table 3. Overview of learning session objectives and activities

Objectives	Didactics and Activities
Learning session 1	
Understand Pathways Project best practices, including identification of patients who are seriously ill	Introduce Pathways project best practices Describe the surprise question as a prognostication tool Kidney Innovations Café; tabletop discussions Goals-of-care conversation training using Veterans Affairs faculty and curriculum based on VitalTalk (8 h total)
Enhance communication skills for shared decision making and advance care planning	Communication skills: responding to emotion, eliciting patient's goals, establishing plans to meet goals Skill practice and role play of common nephrology communication scenarios Responding to patient values
Integrate supportive care into kidney care setting using incremental changes and PDSA cycle	Description of IHI Breakthrough Series, including PSDA cycles Each team plans initial change project with faculty input Develop team charter, including implementation goals Description of data-collection processes Demonstration of data-collection tools
Understand and be prepared for data collection and submission of data for project	
Learning session 2	
Demonstrate steps to conduct advance care planning, shared decision making, and goals of care with patients seriously ill with kidney disease	Enhanced Communication Skills Training: using Ask-Tell-Ask; responding to emotion, empathy Advance care planning discussion with palliative medicine physician Patient panel discussion Video interview with physician leader in MMWD in Australia Breakout session: MMWD for CKD teams Breakout session: palliative dialysis for dialysis center teams
Describe approaches to providing MMWD	Collaborative sharing through storyboards Idea sharing between sites Discipline-specific conversations to address shared concerns Implementation strategies Small tests of change; the PDSA cycle Team working time: fishbone diagram for root cause analysis
Identify ways to implement Pathways best practices for supportive care of patients who are seriously ill	
Apply appropriate steps of IHI Breakthrough model of healthcare improvement techniques to implement small tests of change	
Learning session 3	
Share successes and challenges in implementing supportive care	Visual storyboard presentations Interdisciplinary panel of successful project teams Discuss implementation challenges Plans to overcome challenges; collaborative discussions Data collection
Foster momentum for implementing Pathways best practices	"Fostering-sustainability" lecture Developing a sustainability plan Fishbowl discussion: case study on sustainability plan with one site
Use frameworks for sustainability planning to anchor changes to existing processes and "holding the gains"	Panel of innovative US models transforming the kidney care system How to "nudge" organization culture
Identify opportunities and resources for spread within organization	

PDSA, Plan-Do-Study-Act; IHI, Institute for Healthcare Improvement; MMWD, medical management without dialysis.

communication skills is a regular part of the monthly Pathways action call and is modeled by faculty during site visits. Beginning with the second learning session, the curriculum shifts to emphasize a nephrology-specific form of the Ask-Tell-Ask process that we adapted specifically to address kidney failure issues (Supplemental Material 5).

Implementation of what is learned in the didactic learning sessions is a core aspect of the collaborative. To support implementation, we enlisted an expert quality-improvement advisor to conduct monthly calls with each site to discuss their change efforts and help them plan realistic tests of change, placing emphasis on helping teams integrate the Pathways best practices into the ongoing workflow that is already required of dialysis centers.

Finally, we plan to have Pathways faculty visit the sites in person several times to address questions and provide mentoring on implementation. In particular, one of the faculty will demonstrate goals-of-care conversations using the Ask-Tell-Ask approach (16) with one or two of each dialysis center's patients who are seriously ill, and then debrief with the clinical staff.

Implementation and Effectiveness Study: Design, Setting, and Measurements

The funding organization engaged an external evaluation team who designed a mixed-methods hybrid implementation-effectiveness study (17). The study's timeline for implementation and evaluation, determined on the basis of the funding

organization's parameters, was 18 months. In this hybrid design, dual evaluation of implementation and pilot clinical effectiveness is conducted to facilitate adoption in the real-world setting. The recommended change-package interventions require significant behavior change on the part of the individual clinical team members, changes across levels in an organization, and collaboration with outside partners (hospice and palliative care). In addition, the intervention is intended to be flexible to allow participant teams to choose what they implement and where. Therefore, each clinic is likely to implement a different package of interventions and, after 18 months of implementation, changes will not be fully in place.

The study was approved by the George Washington University Institutional Review Board (IRB).

Design

The evaluation design combines an evaluation conducted by the Pathways Project team, which includes both formative and summative evaluation components and an implementation evaluation conducted by the outside evaluation team. In combination, the evaluation encompasses three related components: (1) effectiveness evaluation (including patient outcomes and staff perception of the effectiveness of the implementation of the change package); (2) quality-improvement monitoring *via* monthly tracking of a suite of quality improvement indicators tied to the change package; and (3) implementation evaluation conducted by the external evaluator, using mixed methods to assess implementation of the collaborative processes.

The effectiveness evaluation will use a prepost design to assess changes in patient-reported outcomes and staff-reported outcomes. Several alternative design options were considered, including randomizing intervention and control clinics, but the participating organizations did not feel this was feasible due to business needs. We also explored the potential for a step-wedge design, but this was not feasible due to program costs and time frame.

Setting

Dialysis organizations involved in an integrated kidney care or value-based purchasing model were invited to participate. The rationale was that these models created incentives, both financial and organizational, to implement innovations. We also recruited a VA Medical Center site because the VA operates within a comprehensive, coordinated care system. However, the VA team joined the project and received IRB approval almost 9 months later than the other sites. Because of the delay, the VA data are not included in the baseline data reported here for the other ten dialysis centers.

The evaluation will include ten dialysis centers, representing a range of geographic regions and treating approximately 1550 patients receiving dialysis. These dialysis centers are part of three medium-size dialysis organizations, two of which are not-for-profit organizations. Three CKD practices associated with the dialysis centers also participated in the learning collaborative, but will not be included in the formal evaluation because the setting and patient population differs so greatly from the dialysis centers.

Data collection will occur at the participant level and at the dialysis center level. Individual-level data collected at baseline and at the end of the study will include patient-reported measures, utilization outcomes for patients who are seriously ill, staff surveys, qualitative observations of collaborative activities, and interviews with implementation teams. Center-level data will include baseline and end-of-study chart audits, and monthly implementation-process measurements.

Measurements

Table 4 lists the study instruments; Table 5 displays the schedule for data collection. There will be two primary outcome measures for the effectiveness evaluation. The primary patient-reported outcome will be quality of end-of-life communication, as measured by the Engelberg quality of communication subscale on end-of-life communication (18). The additional primary outcome measure is change in comprehensive advance care planning documentation, as measured with the chart audit tool developed for the study (Supplemental Material 6a). We explored direct measurement of goal-concordant care as the primary outcome. However, after reviewing many candidate measures, we concluded there was, as yet, no reliable measure for this concept (19–21). Several projects to develop such a measure were in initial stages, but were not yet ready for use.

Secondary outcomes include patient-reported outcomes of engagement in advance care planning, shared decision making, quality of end-of-life communication (Supplemental Material 6b), staff report of supportive-care provision (Supplemental Material 6c), and staff report of implementation (Supplemental Material 6d). Exploratory outcomes include provision of palliative dialysis, withdrawal from dialysis, emergency-department visits, hospitalizations, and hospice admissions.

Patient-Reported Outcomes

Clinicians at each center will use the “surprise question” to identify patients who are seriously ill (22,23). At baseline and end of study, patients identified as seriously ill in the previous 3 months will be invited to complete a telephone survey. Exclusion criteria include age <21 years; impaired cognition, as determined either by dialysis center or by research coordinators; language other than English or Spanish. (The original protocol submitted to ClinicalTrials.gov specified a cutoff age of 18 years. This was modified to 21 years on the advice of the participating sites.) The survey will be administered by telephone by trained interviewers from the West Virginia Clinical and Translational Science Institute. We will use validated survey instruments to assess quality of communication, engagement in advance care planning, and shared decision making among patients who are seriously ill (Table 4).

Chart Audit of Advance Care Planning Documentation

The chart audit will be conducted by research associates, at each site, on the charts of patients identified as seriously ill by dialysis center clinical staff, using a checklist developed for the purpose of this study to assess goals of care documentation (see Supplemental Material 6a for audit tool and instructions). Auditors from each site were trained in the use of the tool by Pathways staff *via* a webinar and provision of

Table 4. Measurement domains and data-collection instruments

Measurement Type/ Data-Collection Method	Subdomain	Instrument
Patient-reported outcomes/telephone survey of patients who are seriously ill (Supplemental Material 6b)	Readiness for advance care planning	Sudore four-item advance care planning survey (31)
	Global quality of communication	Heard and Understood one-item measure (32)
	Quality of communication about end-of-life care	Quality of Communication 13-item questionnaire (18) Two subscales: General communication EOL communication
	Shared decision making Patient demographics	CollaboRATE three-item measure (33) Patient demographics and clinical characteristics
Team-reported outcome/survey (Supplemental Materials 6c and 6d)	Supportive care in practice setting	Kidney Supportive Care Implementation Quotient: Survey developed by Pathways on the basis of the Pathways change package
Quality of advance care planning as recorded in medical record/chart audit (Supplemental Material 6a)	Integration of new practices	NoMAD (34)
	Project progress Completeness of ACP documentation	IHI Project Progress Assessment Scale (35) Chart audit codeveloped by Pathways and Stanford team Elements covered: Decision-making capacity assessed Surrogate named Goals-of-care discussion documented Advance directives discussed and completed if a patient so chooses Medical order(s) completed as appropriate (Do Not Resuscitate or POLST paradigm) form Advance directives retrievable in the electronic health record Advance directives or POLST/medical orders entered in the electronic regional registry if available
Utilization/monthly facility quality indicator report		Patient utilization: Seriously ill indicator Nursing home or assisted-living residence Discontinued dialysis Palliative dialysis Emergency-department visit Hospitalized overnight Admitted to hospice Died Site of death
Nonequivalent dependent variables/monthly facility quality-indicator report		Variables to control for secular trends not affected by Pathways intervention: Missed treatments Patients in nursing homes or assisted living Mean serum albumin for facility

EOL, end of life; IHI, Institute for Healthcare Improvement; ACP, advanced care planning; POLST, Physician or Provider Order for Life-Sustaining Treatment.

detailed audit instructions. The checklist assesses whether the following are present in the chart: (1) decision-making capacity assessment; (2) a Do-Not-Resuscitate or medical order (Medical Order for Life-Sustaining Treatment, also called Physician or Provider Order for Life-Sustaining Treatment in some states); (3) the patient's designated healthcare agent and, if so, whether contact information

was also present; (4) an advance directive and, if so, whether a copy of it was present; (5) a goals-of-care discussion and, if present, what the patient's preferences were; and (6) an advance directive or medical order and whether it had been placed in the local hospital electronic medical record system and/or regional or statewide registry.

Measure	Mo 0; LS-1	Mo 0–6; Action Period 1	Mo 6; LS-2	Mo 7–11; Action Period 2	Mo 12; LS-3	Mo 13–16; Action Period 3	Mo 16–18; Follow-Up Data Collection
Patient-reported outcomes							
Patient telephone survey		Once					Once
Team-reported outcomes							
KSC-IQ (all staff)		Once					Once
NoMAD (change team staff only)		Once		Once		Once	
Quality of advance care planning							
Advance care planning chart review for patients who are seriously ill		Once					Once
Patient-level data							
Demographics and service utilization of patient who is seriously ill		Monthly May–July					Monthly July–September
Facility-level quality indicators							
Aggregate utilization and quality indicators		Monthly		Monthly		Monthly	Monthly

LS, learning session; KSC-IQ, Kidney Supportive Care Implementation Quotient.

Nonequivalent Dependent Variables

In addition to measuring process outcomes that we expect to change, we also plan to measure processes that we do not expect to be affected by the intervention. Use of such nonequivalent dependent variables is a technique used in quasi-experimental designs to mitigate internal threats to validity in such quasi-experimental designs (24). We chose three nonequivalent dependent variables: number of missed treatments; number of patients living in nursing homes or assisted living; and mean serum albumin, which we thought might be affected by secular trends but not by the Pathways intervention.

Implementation Processes and Outcomes

Implementation processes and outcomes will be assessed using mixed methods, including surveying dialysis center implementation teams on integration of change-package elements into routine work, observation of collaborative activities, and interviews with a subset of implementing teams at the end of the study. Implementation outcomes will use the framework of Proctor *et al.* (25). The dialysis center staff will complete one survey at baseline and end of study (Kidney Supportive Care Implementation Quotient [KSC-IQ]) and a second survey during implementation and at the end (NoMAD survey; Normalization Process Theory, available at <http://www.normalizationprocess.org/nomad-study/>). The KSC-IQ assesses staff perception of how well their organization delivers 17 components of kidney supportive care. Survey questions are scored on a Likert scale from one to three, and are tied to the best practices in the evidence-based change package. The NoMAD survey measures implementation processes from the perspectives of implementers; the measure was only perceived to be appropriate once the sites were familiar with the new practices and could judge their utilization (*i.e.*, after learning session 1). Both surveys can be completed either online or on paper.

Utilization

The evaluation will include several exploratory utilization outcomes. These include goals-of-care conversations held within 30 days of discharge from the hospital, frequency of palliative dialysis (defined as nonstandard dialysis schedule or prescription), dialysis withdrawal, the number of emergency-department visits and hospitalizations, hospice admissions, and site of death. Utilization measures will be collected monthly for all patients identified as seriously ill in the previous month.

Baseline Participant Demographic Data, Baseline Chart Audit, and Feasibility of Data Collection Study Participants

During the 3-month baseline period, the average total census at the ten reporting dialysis facilities was 1544 patients. (The protocol filed with ClinicalTrials.gov specified a 4-month baseline period. This was shortened to 3 months due to delays in IRB approval which delayed the start of the patient telephone survey.) Sites screened 98% of patients each month and identified 19% as seriously ill. As expected, the census of patients who were seriously ill varied from month to month as new patients were identified, while others died or were transferred to other centers. This resulted in a cumulative total

of 335 patients who were seriously ill at baseline, of whom 179 (53%) initially agreed to be contacted. Of these 179 patients, we reached 59 (33%) with up to three contact attempts. The reasons for surveys not being completed were that 61 patients could not be reached by phone (no answer or voice mailbox full), 49 declined to participate once reached (not interested or did not feel well or were too cognitively impaired), and ten died before they could be contacted. Table 6 presents the demographics for the patients who were surveyed and those who were not. The majority of patients in both groups were White, ≥ 65 years old, and had been on dialysis ≥ 3 years. The significant differences between the groups were that the surveyed group had higher percentages of Black patients and of English-speaking patients, and a lower percentage of Asian patients, perhaps because of language barriers ($P=0.02$ for race; $P=0.01$ for primary language).

Chart Audit

The chart audit was conducted on 267 (94%) of 284 patients who were identified as seriously ill in the first month of the baseline period (May 2019). Charts were rated as containing complete, partial, or no information on each variable. (Figure 2) Across all sites, 181 charts (68%) contained complete information about the patient's designated healthcare agent, including how to contact the agent; 40 (15%) had partial information; and 46 (17%) had no information. Documentation of assessment of decision-making capacity was complete in 58 charts (22%), partial in 89 (33%), and missing in 120 (45%). Documentation of a goals-of-care discussion, including the patient's particular preferences, was found in 100 charts (38%), with no goals-of-care discussion noted in 110 charts (41%). A copy of an advance directive was retrievable from 101 charts (38%); a statement that the patient had an advance directive, without the document being available in the chart, was found for 15 patients (6%); and 151 charts (56.6%) had no information about an advance directive. Medical orders—such as Do Not Resuscitate or Medical Order for Life-Sustaining Treatment/Physician or Provider Order for Life-Sustaining Treatment—were even rarer in the charts of these patients who were seriously ill; they were only present in 40 charts (15%).

Dialysis Staff Survey

For the baseline KSC-IQ survey, 156 staff submitted responses *via* either email or an online portal. Sites were asked to distribute the survey widely to all staff at the center. The number of returned surveys varied widely, from three responses at one site to 31 at another site.

Discussion

The Pathways Project is a novel approach to address the major clinical problem of poor-quality end-of-life care for many patients receiving dialysis. It is the first effort in the United States to standardize elements of kidney supportive care and implement them in multiple sites that are part of multiple dialysis organizations. To our knowledge, it is also the first time that a learning-collaborative model has been used to guide implementation of kidney supportive care. As called for in the Breakthrough Collaborative model, an

Table 6. Demographics of patients who were seriously ill by baseline interview status, N=335

Variables	Interviewed (N=59), N (%)	Not Interviewed (N=276), N (%)	P Value	Missing (%)
Male sex	30 (51)	165 (60)	0.25	0.3
Age group (yr)			0.72	2
<55	7 (12)	31 (12)		
55–64	15 (25)	67 (25)		
65–74	23 (39)	85 (32)		
75–84	8 (14)	55 (20)		
≥85	6 (10)	31 (12)		
Race			0.02	0.6
White	32 (54)	168 (61)		
Black	22 (37)	59 (22)		
Asian	1 (2)	27 (10)		
Other	4 (7)	20 (7)		
Non-Hispanic Ethnicity	40 (74)	172 (69)	0.60	10
Medicaid=yes	26 (53)	140 (63)	0.29	18
Primary language			0.01	24
English	45 (92)	151 (73)		
Spanish	4 (8)	36 (18)		
Other	0 (0)	19 (9)		
Years on dialysis			0.98	0.3
<1 yr	10 (17)	48 (18)		
1–2 yr	18 (31)	80 (29)		
≥3 yr	31 (53)	147 (54)		
Site			0.23	0.0
Site 1	2 (3)	10 (4)		
Site 2	12 (20)	49 (18)		
Site 3	2 (3)	28 (10)		
Site 4	5 (9)	11 (4)		
Site 5	10 (17)	22 (8)		
Site 6	3 (5)	23 (8)		
Site 7	3 (5)	15 (5)		
Site 8	8 (14)	26 (9)		
Site 9	4 (7)	25 (9)		
Site 10	10 (17)	67 (24)		

evidence-based change package will provide the content guidance as teams work to set and achieve improvement goals. To improve supportive care practices, all teams are asked to implement the following interventions: to

systematically identify patients who are seriously ill; conduct shared decision-making and advance care planning conversations with them; and respond, when appropriate, with palliative dialysis options or supported options for

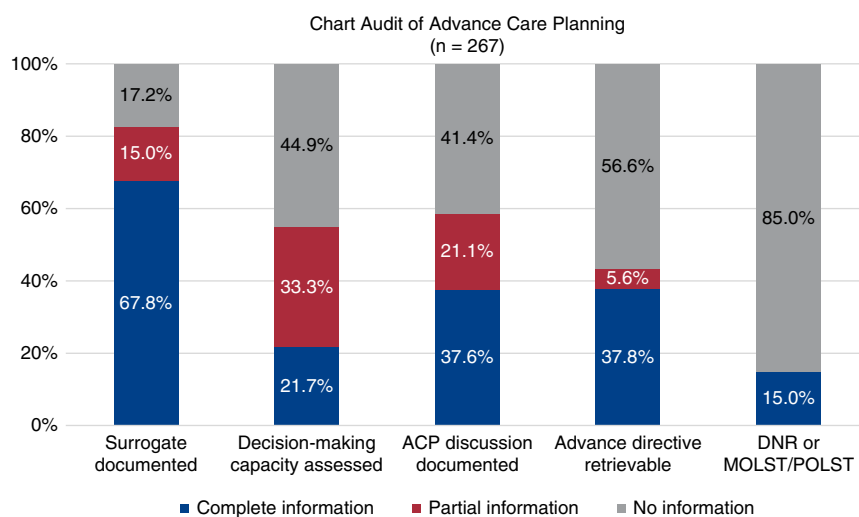


Figure 2. | Baseline documentation of advance care planning in charts of seriously ill patients. Availability of complete information about different components of advance care planning varied, from high of 68% of patients with complete information about a surrogate, to low of 15% of information with a medical order such as DNR or POLST accessible in the chart. ACP, advance care planning; DNR, Do Not Resuscitate; MOLST, Medical Order for Life-Sustaining Treatment; POLST, Physician or Provider Order for Life-Sustaining Treatment.

stopping dialysis, including hospice referral. The education about, and implementation of, kidney supportive care best practices will be reinforced by a collaborative learning approach among the dialysis center teams with monthly calls to share what each has learned about successful implementation; monthly quality metrics to track trends in supportive care best practices, allowing formative evaluation; and monthly calls with the Pathways quality-improvement advisor to discuss each site's monthly reports and implementation change efforts, and to help them plan realistic incremental tests of change.

In selecting the best practices for implementation, and in designing the data-collection processes, we placed a premium on feasibility within existing dialysis center resources. Although it may be argued that all patients in a dialysis center would benefit from supportive care practices, it is easier to persuade busy clinicians to start with a smaller, high-priority subset of patients. This approach has been recommended by others for introducing goals-of-care discussions into the dialysis center (26,27). It addresses the major barrier of time limitations, which is often cited as a reason clinicians do not conduct advance care planning (26–28), and is consistent with change theories that recommend reducing barriers and friction that may impede adoption of a change (29).

A goal of a learning collaborative is to enable participants to adapt the change-package components to local conditions and culture; thus, implementation is not rigorously protocolized in the way that a clinical efficacy trial is conducted. Evaluation of multicomponent, complex interventions, such as Pathways, can be challenging (30). The evaluation is designed to capture a range of information to paint a full qualitative and quantitative picture of the experience of participants in the collaborative and the outcomes produced.

Our baseline data collection showed that the chart audit was feasible, but that it was very difficult to recruit patients who were seriously ill for the telephone survey. Chart audits were completed for 94% of patients who were seriously ill, with very little missing data. However, baseline telephone surveys were only completed for 18% of patients who were seriously ill. The main barriers were language (the survey was offered in English and Spanish, but not in other languages), cognitive limitations, and patients' unwillingness to respond to phone calls. However, the patients who did complete the telephone survey at baseline were demographically similar to those patients who did not complete the survey, other than in regards to race and language. Future studies of participants who are seriously ill may need to consider approaches to increase response rates, such as face-to-face or on-dialysis interviews, or the use of substituted proxy reports.

A limitation to this study is the quasi-experimental, prepost design without a control group. Prepost designs are subject to several threats to internal validity, particularly secular trends. However, resource limitations and business considerations of the participating organizations made control groups infeasible. We expect that the mixed-methods design will provide rich qualitative information to supplement the trend data, thus strengthening the ability to assess whether secular trends played a minimal or strong role in the outcomes.

The TEP recommended that we measure the outcome of goal-concordant care, but no validated measure was available. Instead, we used surrogate markers of the process that are thought to influence, and lead to, achieving goal-concordant care. We created the KSC-IQ survey as a novel measure of kidney supportive care implementation. It was developed for this project on the basis of a review of the literature and expert review for face and content validity; it has not undergone psychometric testing. There are no comparisons or established norms for the KSC-IQ.

The Pathways change-package, best-practice recommendations are determined on the basis of a literature review and consensus of the TEP convened for the Pathways Project. Although we believe they accurately represent the state-of-the-art interventions with regard to kidney supportive care, they have not been subjected to an evidence-grading process, which would be difficult to do due to the lack of clinical trials in this area.

Very few studies have explicitly focused on enrolling patients seriously ill with kidney failure, and monitoring the outcomes that matter to these patients. Even fewer studies have focused on the implementation of supportive care practices. The Pathways Project is innovative because it will help to fill the knowledge gap of how to improve the quality of supportive care for patients seriously ill with kidney failure.

In conclusion, numerous national and international reports have documented the gaps in the quality of care for patients seriously ill with kidney failure, but there is, as yet, little guidance on the specific practices and implementation methods that will effectively address this gap. The Pathways Project will test whether a learning-collaborative approach can help to close this gap. We expect to learn valuable lessons about what fosters, and what impedes, the effort of dialysis centers to incorporate the Pathways intervention into their usual workflow processes to improve kidney supportive care for their patients.

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Author Contributions

A. Aldous, G. Harbert, L. Holdsworth, D. E. Lupu, M. Kurella Tamura, and A. H. Moss wrote the original draft; A. Aldous, L. Holdsworth, and M. Kurella Tamura were responsible for formal analysis; A. Aldous, L. Holdsworth, M. Kurella Tamura, D. E. Lupu, and A. H. Moss were responsible for data curation; G. Harbert, D. E. Lupu, A. H. Moss, A. Nicklas, and B. Vinson were responsible for project administration; L. Holdsworth, M. Kurella Tamura, D. E. Lupu, and A. H. Moss were responsible for investigation and methodology; L. Holdsworth, M. Kurella Tamura, D. E. Lupu, A. H. Moss, and B. Vinson were responsible for funding acquisition; D. E. Lupu and A. H. Moss conceptualized the study, were responsible for resources, and provided supervision; and all authors reviewed and edited the manuscript.

Supplemental Material

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Supplemental Material 1. Literature search terms and strategy.
Supplemental Material 2. Interview guide for interviews of implementation leaders.

Supplemental Material 3. Questions for the Technical Expert Panel meeting.

Supplemental Material 4. Pathways Project Change Package – 1-page summary.

Supplemental Material 5. Ask-Tell-Ask card.

Supplemental Material 6. Evaluation data collection and survey instruments: a. Chart audit instructions; b. Patient survey instrument; c. KSC-IQ staff survey; d. NOMAD adaptation.

References

1. Kurella Tamura M, O'Hare AM, Lin E, Holdsworth LM, Malcolm E, Moss AH: Palliative care disincentives in CKD: Changing policy to improve CKD care. *Am J Kidney Dis* 71: 866–873, 2018 <https://doi.org/10.1053/j.ajkd.2017.12.017>
2. Brown L, Gardner G, Bonner A: A comparison of treatment options for management of end stage kidney disease in elderly patients: A systematic review. *JBI Database Syst Rev Implement Rep* 11: 197–208, 2013 <https://doi.org/10.11124/jbisir-2014-1152>
3. Wachterman MW, Pilver C, Smith D, Ersek M, Lipsitz SR, Keating NL: Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med* 176: 1095–1102, 2016 <https://doi.org/10.1001/jamainternmed.2016.1200>
4. Lupu D, Nyirenda J; Coalition for Supportive Care of Kidney Patients (CCKP): Creating kidney supportive care programs: Lessons learned around the world, 2018. Available at: <https://go.gwu.edu/creatingkidneysupportivecareprograms>. Accessed September 29, 2020
5. Institute for Healthcare Improvement: The breakthrough series: IHI's collaborative model for achieving breakthrough improvement. Boston, Institute for Healthcare Improvement, 2003
6. Nix M, McNamara P, Genevro J, Vargas N, Mistry K, Fournier A, Shofer M, Lomotan E, Miller T, Ricciardi R, Bierman AS: Learning collaboratives: Insights and a new taxonomy from AHRQ's two decades of experience. *Health Aff (Millwood)* 37: 205–212, 2018 <https://doi.org/10.1377/hlthaff.2017.1144>
7. Wells S, Tamir O, Gray J, Naidoo D, Bekhit M, Goldmann D: Are quality improvement collaboratives effective? A systematic review. *BMJ Qual Saf* 27: 226–240, 2018 <https://doi.org/10.1136/bmjqs-2017-006926>
8. ØVretveit J, Bate P, Cleary P, Cretin S, Gustafson D, McInnes K, McLeod H, Molfenter T, Plsek P, Robert G, Shortell S, Wilson T: Quality collaboratives: Lessons from research. *Qual Saf Health Care* 11: 345–351, 2002 <https://doi.org/10.1136/qhc.11.4.345>
9. Improving Chronic Illness Care: Change package: Improving chronic illness care. Available at: http://www.improvingchroniccare.org/index.php?p=Change_Package&s=386. Accessed September 29, 2020
10. Institute for Healthcare Improvement: Science of improvement: Spreading changes. Boston, Institute for Healthcare Improvement. Available at: <http://www.ihl.org:80/resources/Pages/How-toImprove/ScienceofImprovementSpreadingChanges.aspx>. Accessed September 29, 2020
11. Renal Physician's Association: Shared decision-making in the appropriate initiation of and withdrawal from dialysis: Clinical practice guideline. Rockville, MD, Renal Physician's Association, 2010
12. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, Murtagh FEM, Naicker S, Germain MJ, O'Donoghue DJ, Morton RL, Obrador GT; Kidney Disease: Improving Global Outcomes: Executive summary of the KDIGO Controversies conference on supportive care in chronic kidney disease: Developing a roadmap to improving quality care. *Kidney Int* 88: 447–459, 2015 <https://doi.org/10.1038/ki.2015.110>
13. Nembhard IM: Learning and improving in quality improvement collaboratives: Which collaborative features do participants value most? *Health Serv Res* 44: 359–378, 2009 <https://doi.org/10.1111/j.1475-6773.2008.00923.x>
14. U.S. Department of Veterans Affairs National Center for Ethics in Health Care: Goals of care conversations skills training for physicians, advance practice nurses, and physician assistants. Washington DC, U.S. Department of Veterans Affairs National Center for Ethics in Health Care, 2019. Available at: <https://www.ethics.va.gov/goalsofcaretraining/practitioner.asp>. Accessed October 29, 2020
15. VitalTalk. Available at: <http://www.vitaltalk.org/>. Accessed September 29, 2020
16. Lupu D, Moss A; Using "Ask-Tell-Ask" in person-centered care: Promoting goals of care conversations with dialysis patients and their families during COVID-19. Supportive strategies for kidney care community during COVID-19: Communication series. Coalition for Supportive Care of Kidney Patients. Available at: <http://go.gwu.edu/GOCconversations>. Accessed October 1, 2020

17. Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C: Effectiveness-implementation hybrid designs: Combining elements of clinical effectiveness and implementation research to enhance public health impact. *Med Care* 50: 217–226, 2012 <https://doi.org/10.1097/MLR.0b013e3182408812>
18. Engelberg R, Downey L, Curtis JR: Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. *J Palliat Med* 9: 1086–1098, 2006 <https://doi.org/10.1089/jpm.2006.9.1086>
19. Halpern SD: Goal-concordant care — searching for the holy grail. *N Engl J Med* 381: 1603–1606, 2019 <https://doi.org/10.1056/NEJMp1908153>
20. Sanders JJ, Curtis JR, Tulsy JA: Achieving goal-concordant care: A conceptual model and approach to measuring serious illness communication and its impact. *J Palliat Med* 21: S17–S27, 2018
21. Turnbull AE, Hartog CS: Goal-concordant care in the ICU: A conceptual framework for future research. *Intensive Care Med* 43: 1847–1849, 2017 <https://doi.org/10.1007/s00134-017-4873-2>
22. Moss AH, Ganjoo J, Sharma S, Gansor J, Senft S, Weaner B, Dalton C, MacKay K, Pellegrino B, Anantharaman P, Schmidt R: Utility of the “surprise” question to identify dialysis patients with high mortality. *Clin J Am Soc Nephrol* 3: 1379–1384, 2008 <https://doi.org/10.2215/CJN.00940208>
23. White N, Kupeli N, Vickerstaff V, Stone P: How accurate is the ‘surprise question’ at identifying patients at the end of life? A systematic review and meta-analysis. *BMC Med* 15: 139, 2017 <https://doi.org/10.1186/s12916-017-0907-4>
24. Coryn CLS, Hobson KA: Using nonequivalent dependent variables to reduce internal validity threats in quasi-experiments: Rationale, history, and examples from practice. *New Dir Eval* 2011: 31–39, 2011 <https://doi.org/10.1002/ev.375>
25. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, Hensley M: Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Adm Policy Ment Health* 38: 65–76, 2011 <https://doi.org/10.1007/s10488-010-0319-7>
26. Mandel EI, Bernacki RE, Block SD: Serious illness conversations in ESRD. *Clin J Am Soc Nephrol* 12: 854–863, 2017 <https://doi.org/10.2215/CJN.05760516>
27. Goff SL, Unruh ML, Klingensmith J, Eneanya ND, Garvey C, Germain MJ, Cohen LM: Advance care planning with patients on hemodialysis: An implementation study. *BMC Palliat Care* 18: 64, 2019 <https://doi.org/10.1186/s12904-019-0437-2>
28. Lockett T, Sellars M, Tieman J, Pollock CA, Silvester W, Butow PN, Detering KM, Brennan F, Clayton JM: Advance care planning for adults with CKD: A systematic integrative review. *Am J Kidney Dis* 63: 761–770, 2014 <https://doi.org/10.1053/j.ajkd.2013.12.007>
29. Kotter JP, Schlesinger LA: Choosing strategies for change. *Harv Bus Rev* 57: 106–114, 1979
30. Nadeem E, Olin SS, Hill LC, Hoagwood KE, Horwitz SM: Understanding the components of quality improvement collaboratives: A systematic literature review. *Milbank Q* 91: 354–394, 2013 <https://doi.org/10.1111/milq.12016>
31. Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ: Measuring advance care planning: Optimizing the advance care planning engagement survey. *J Pain Symptom Manage* 53: 669–681.e8, 2017 <https://doi.org/10.1016/j.jpainsymman.2016.10.367>
32. Gramling R, Stanek S, Ladwig S, Gajary-Coots E, Cimino J, Anderson W, Norton SA, Aslakson RA, Ast K, Elk R, Garner KK, Gramling R, Grudzen C, Kamal AH, Lamba S, LeBlanc TW, Rhodes RL, Roeland E, Schulman-Green D, Unroe KT; AAHPM Research Committee Writing Group: Feeling heard and understood: A patient-reported quality measure for the inpatient palliative care setting. *J Pain Symptom Manage* 51: 150–154, 2016 <https://doi.org/10.1016/j.jpainsymman.2015.10.018>
33. Barr PJ, Thompson R, Walsh T, Grande SW, Ozanne EM, Elwyn G: The psychometric properties of CollaboRATE: A fast and frugal patient-reported measure of the shared decision-making process [published correction appears in J Med Internet Res 17: e32, 2015 10.2196/jmir.4272]. *J Med Internet Res* 16: e2, 2014 <https://doi.org/10.2196/jmir.3085>
34. May C, Rapley T, Mair FS, Treweek S, Murray E, Ballini L, Macfarlane A, Girling M, Finch TL: Normalization process theory on-line users’ manual, toolkit and NoMAD instrument, 2015 Available at: <http://www.normalizationprocess.org>. Accessed August 18, 2018
35. Institute for Healthcare Improvement: IHI Assessment Scale for Collaboratives. Boston, Institute for Healthcare Improvement. Available at: <http://www.ihl.org/resources/Pages/Tools/AssessmentScaleforCollaboratives.aspx>. Accessed August 14, 2018

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Supplemental Materials

1. Literature search terms and strategy
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Supplement 1: Search Terms for focused Literature Review

Search Terms for Focused Literature Review:

active medical management without dialysis

bereavement care

chronic kidney disease

chronic kidney failure

chronic renal failure

CKD

communication

comprehensive conservative care

conservative care

conservative kidney management

conservative management

conservative, non-dialytic management

disease, end stage kidney

disease, end stage renal

emergency care

emotional support

end stage kidney disease

end stage renal disease

end stage renal failure

ER

health resource

healthcare resources

hospice

hospice care

hospice program

hospital mortality

hospital readmission

hospitalization

intensive care

kidney disease, end stage

maximal conservative management

morbidity

mortality

non-dialytic management

outcome and process assessment health care

outcomes

pain management

pre ESRD

prognosis

quality of life

renal disease, end stage

renal failure, end stage

renal palliative care

renal supportive care

spiritual support

symptom assessment

symptom management

Supplement 2: Pathways Project Change Package



Pathways Project CHANGE PACKAGE

Evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.



Supportive Care Capacity

Create the System

1. Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
2. Assess unmet supportive care needs in patient population
3. Provide education to staff on the principles and practices of primary supportive care, including communication skills
4. Collaborate with palliative care/hospice specialists



Values Guide Care

Elicit & Respect Patient Values and Preferences

5. Implement shared decision-making for current and advance care planning for future care options **
6. Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
7. Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings



Just Right Care

The Right Care to the Right Person at the Right Time

8. Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions **
9. Provide medical management without dialysis to patients avoiding or delaying dialysis
10. Screen and manage pain and symptoms
11. Assess psychological and spiritual needs and address needs
12. Proactively identify and manage patients at high-risk for frequent hospital readmission



Throughout the Continuum

Enhanced Support at the End of Life

13. Coordinate care and care transitions with specialty palliative care and hospice
14. Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients **

****Indicates a mandatory practice that project participants are required to test and implement**

Supplement 3: Ask-Tell-Ask card



The Ask-Tell-Ask Approach to Conversations
with Seriously Ill Patients with Kidney Disease*
Alvin H. Moss, MD, FACP, FAAHPM

ASK

- **Build trust and strengthen relationship**
 - “I would like to be able to respect your wishes for future medical care. Would it be ok for us to talk about what you would want?”
 - “How are you doing compared to a year ago?”
- **Assess patient/family understanding of the patient’s medical condition and prognosis**
 - “What have physicians told you about your (the patient’s) condition?”
 - “What is your understanding of your (the patient’s) major medical problem now?”
 - “How serious is it?”
- **Determine patient’s goals for treatment in his/her present condition?**
 - “How much information about what is likely to be ahead with your illness would you like from our team?”
 - “What is most important to you in receiving treatment for your illness? What do you hope for?”
 - “What would you want to avoid in receiving treatment for illness (some patients say they would want to avoid being placed on a breathing machine or in a nursing home)? What do you fear?”
- **What are your most important goals if your health situation worsens?**
 - To the health care proxy, “If your _____ (mother, father, etc) was mentally clear and could see what condition he/she is in what would he tell us to do? Are there things he or she would want us to avoid in his/her treatment?”

MEDICARE BILLING CODES FOR ADVANCE CARE PLANNING

99497 16 minutes or longer of first 30 minutes
99498 add on to 99497-includes 30 minutes from 99497 and at least 16 minutes for 99498 for at least 46 minutes of advance care planning

- **Explore understanding of who the patient wants to be his/her healthcare proxy and what the role of the proxy should be.**
 - “Who would you want to make medical decisions for you if you became too sick to make them yourself?”
 - To the patient’s health care proxy, “What do you understand about your role as the healthcare proxy? How are you to make decisions?” (NB: Proxy is to make decisions based upon the patient’s expressed wishes or, if unknown, the patient’s best interest.)

TELL

- **Explain the patient’s overall condition emphasizing the patient’s most serious comorbidities**
- **Discuss likely future complications**
- **Assist with informed decision about breathing machine, ICU, and CPR**
 - “Have you been on a breathing machine before? If you got sick, would you want to be on one again if necessary to keep you alive? To proxy, “Has the patient been on a breathing machine before? Has he/she said anything about wanting/not wanting to be on a breathing machine?”
 - “It is helpful to learn what is most important to you. Would you want—to live as long as possible regardless of pain and suffering or to live a shorter period of time to avoid pain and suffering? (75% of dialysis patients want to live a shorter time to avoid pain and suffering)
 - “Under what circumstances if any would you want to stop dialysis?” (Most patients say if they had a large stroke and were unconscious or if they had severe dementia they would not want to be kept on dialysis)
 - CPR is not as successful as most people think. Would you want those treating you to attempt CPR if your heart stopped? If you live through CPR, you will be on a breathing machine. Is that what you would want?

ASK

- **What questions do you have?**
- **What will you tell your family about what we discussed?**
- **In your own words, please tell me what you understand from our conversation.**

*Reference: Mandel EI, et al. Serious Illness Conversations in ESRD. Clin J Am Soc Nephrol 2017;12:854-863.

Supplement 4: Interview guide for interviews of implementation leaders

Interview guide for discussions with model programs or places with innovative practices

Introduction

- Brief overview of Pathways project – looking for tools, practices, examples for any of the pathways
- Consent to record the interview for purposes of transcribing it.
- Consent to share information about program with Pathways TEP. Further dissemination – we would come back to you for further permission.

Description of the program

- What services are provided?
- Who is served? (get actual numbers served if applicable)
- Staffing?
- Funding?

History

- How did it get started?
- What do you consider the successes to date?
- What have been barriers to success or to implementation?
- How did you overcome barriers (if you did)?

Effectiveness

- How are you measuring effectiveness?
- If formal measurement – what measures being used?
- What data is available on effectiveness? Willing to release any internal data to us?
- Are there any formal studies of the program's impact published? Or underway?
- What data do you have on cost, cost effectiveness, cost savings?

Tools to share

- What are the tools, policies/procedures, educational materials being used?
- Will you share samples? If CSCKP likes the material, are you open to dissemination through Pathways project? (Discussion of attribution, licensing, etc would need to follow.)

Lessons learned

- Lessons learned from developing and using these practices?

Snowball

- Snowball – who else do you know of who is doing useful work in this area?

Supplement 5: Questions for the Technical Expert Panel meeting

TEP – What are we hoping to answer?

1. What are the most effective changes* needed to help CKD patients make an informed and supported choice either for dialysis with integrated supportive care or for comprehensive conservative care?
2. What structure, process and resources are needed to effectively provide comprehensive conservative care for patients who choose it?
3. What are the most effective changes needed to help dialysis patients receive supportive care throughout the kidney care continuum?
4. What are the most effective changes needed to help dialysis patients make an informed and supported choice to discontinue dialysis?
5. Are there certain changes that need to be bundled or sequenced in order to maximally effective?
6. What are the most effective measures to help understand whether changes made are improvements?

*Changes might include:

structure of care

care processes

education for providers, patients, family

clinical tools (such as symptom algorithms or trigger lists for PC consultation)

Supplement 6: Evaluation data collection and survey instruments

- a. Chart audit instructions
- b. Patient survey instrument
- c. KSC-IQ
- d. NOMAD adaptation

Supplement 6a: Chart audit instructions

Instructions for Pathways Follow-Up Chart Audit of Advance Care Planning in Records of Seriously Ill Patients

A follow-up audit of the records of patients who have been identified as seriously ill is to be completed once for each patient by October 5, 2020. The goal is to determine the extent to which information about patient advance care planning goals are documented in the medical record.

A HIPAA full waiver of consent has been obtained from your institution, giving us permission to access the medical records for this purpose. **The information gathered must be de-identified before submitting to Pathways.**

Selecting patient records to audit

Your clinic will be developing a list of patients identified as seriously ill at the beginning of each month. Obtain the lists of patients whom your clinic identified as seriously ill at the beginning of July, August, and September 2020. If conducting this audit at a dialysis center, delete new patients. Specifically, delete any patients who had NOT started dialysis by April 1, 2020.

Searching the EHR

If your clinic has designated a specific place in the chart where advance care planning information is entered, you will search that area first. Record whatever you find in this area as it relates to the data collection items on the spreadsheet. If you do not find the relevant information in that area, you will then search other areas, such as progress notes. Search these areas only back to April 1, 2019. Spend no more than 10 minutes looking up information for each patient. The rationale is that if a provider can't find relevant information about goals of care in 10 minutes, then the information is not in a meaningfully retrievable format. Only information on conversations or documents entered **prior to July 10, 2020** is to be captured.

- First go to area specified for ACP in the chart.
- Then search chart going back no farther than April 1, 2019 and spending no more than 10 minutes per patient, (whichever is less time).
- Only record data for discussions or documents entered into the chart **prior to July 10, 2020**.

Recording the data

- Enter the data into an Excel spreadsheet using the template provided: **"ACP Chart Audit Template.xlsx"**.
- When complete, de-identify the data by removing the MRN and any other identifying information you may have added.
- Save as a de-identified file.

Submitting the data

- Email the spreadsheet using secure email to: pathways_data@gwu.edu OR
- Upload the data to the REDCap project “Pathways”, instrument “Follow-up ACP Chart Audit”.

Definitions

Decision Making Capacity (DMC) Assessed

0=no information recorded about whether DMC assessed

1= clear statement that patient has capacity or not – without any documentation about rationale

2= statement that patient has capacity or not, including documentation of rationale. Expected documentation might include elements such as:

- patient does/does not understand his/her medical condition or
- patient does not remember information provided about his condition earlier in visit or previous visit
- patient is able/not able to weigh the consequences of treatment options
- patient has communicated a choice.

Health care agent/Surrogate named

A surrogate (also called health care proxy, durable power of attorney for health care, medical power of attorney, or health care agent depending on the state) is someone that the patient has named to be able to make medical decisions on the patient’s behalf, if the patient is not able to make decisions for him/herself. For this variable, look for information recorded in the record in an area for surrogate information, on a form for surrogate information used in some states, or in the notes. You do NOT need to look inside an advance care planning form or on POLST/MOLST form.

0=no information recorded whether a surrogate has been named

1= clear statement that patient has declined to name a surrogate

2= statement that patient has named surrogate, but name is not provided (e.g. “sister is surrogate” – but sister’s name not given. The reason this is important is in case where it turns out there are two sisters).

3= Surrogate has been named by patient, name is clearly recorded, but no contact information is recorded.

4 – Name and contact information of surrogate is recorded.

Goals of Care conversation documented

0=no information on goals of care found within 10 minutes of search, or since January 2018.

1= A goals of care conversation is documented, with evidence of the choices selected by patient, but documentation is only from template or checklist.

2= Goals of care conversation is documented, and notes have been personalized to clearly show individual preference. For instance, quotes from patient are included, such as “Patient stated “I’m a fighter, so I would never want to give up.” Or “Patient says “I’ve had a good life, so I’d like to have a gentle end. Just keep me comfortable.”

Date of most recent goals of care conversation or advance care planning conversation

Record month and year of most recent conversation documented. DO NOT RECORD day of the date.

Who conducted most recent GOC or ACP conversation?

Record the person who signed the note of the most recent discussion.

0=unknown

1=nephrologist

2=NP

3=social worker

4=team

5=other

Orders or POLST/MOLST Retrievable in chart

This refers to orders signed by physician or NP, usually using a form for that purpose such as POLST or MOLST. May also include notation of DNR orders or other end of life comfort set orders.

0=absence of any orders such as DNR, POLST, MOLST

1= DNR, POLST, MOLST, LST or other standard end of life order set is in chart

Advance Directive Retrievable in chart

This refers to a form completed by the patient, rather than orders signed by clinician, which is captured above.

0=no evidence patient has completed an advance directive

1= Statement that patient has completed an advance directive, but the document is not accessible in the chart.

2= The advance directive form is retrievable from the chart.

Patient advance directives are in an electronic registry

0= no evidence patient's advance directives or POLST are in a registry accessible to other providers

1= patient's advance directive or POLST has been entered in an electronic registry, such as state registry

Other evidence of ACP

If other evidence of advance care planning found that was not captured by previous questions, record a brief description here.

Optional Notes

Briefly describe any other anomalous or notable information here that was not captured in prior questions.

Supplement 6b: Patient survey instrument

Patient Survey Instrument - English
Record ID
Unique Patient ID
PATIENT CONSENT: IRB approved consent script to be inserted here.
Introduction letter was read to participant? Yes / No
Did patient agree to participate? Patient agreed to participate / Patient did not agree to participate
If patient provided a reason for declining, please specify:
Interview Start Time:
Patient Pre-and Post-Intervention Questionnaire
Research team to read to participant and administer the test:
Patients with kidney disease sometimes have memory problems. The first set of the questions is to test your memory. It should take 5 minutes or less.
MoCA-5 Minute Test
Memory:
Immediate Recall
Face Velvet Church Daisy Red
No / Yes
Score: _____
(/5, 1 point for each word)
Fluency: _____
Number of animals named in 1 minute
Score: _____
(/9, 0.5 point for each animal named)
Fluency Calculated Score:
Orientation
Date Month Year Day Place City
No / Yes
Score: _____
(/6, 1 point for each)
Memory:
Delayed Recall

<p>Face Velvet Church Daisy Red</p>
<p>No / Yes</p>
<p>Score:</p> <p>_____</p> <p>(/10, 2 points for each word recalled)</p>
<p>Total Score:</p> <p>_____</p> <p>(/30)</p>
<p>Next, we will collect your address to mail your gift card. Once this is completed, that will conclude this interview. Thank you for your time!</p>
<p>Notice: Due to the patient scoring below a 23, their responses may not be fully accurate.</p>
<p>Interview terminated / Interview continued</p>
<p>Research team to read to participant and administer the test:</p>
<p>Now I have a few questions about you.</p>
<p>Demographics</p>
<p>Dialysis Center or CKD Clinic:</p>
<p>Gender:</p> <p>Male Female Prefer not to say Other</p>
<p>If other, please explain</p>
<p>Age: (in years)</p>
<p>Ethnicity:</p> <p>Hispanic or Latino Not Hispanic or Latino</p>
<p>Race:</p> <p>American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Prefer not to say Other</p>
<p>If other, please explain</p>
<p>Primary language spoken by patient:</p> <p>English Spanish Chinese Russian Other</p>
<p>If other, please specify</p>
<p>Education: (in years)</p>

Is patient on Medicaid?
Yes / No / Unknown
Address (this will be used to mail the participants gift card)
Years on Dialysis: (in years)
Number of times hospitalized in the last year:
Karnofsky Performance Status Score categories
Do you live alone?
Yes / No
What are you able to do?
Able to carry on normal activity and work
Unable to work but able to live at home and care for most personal needs
Unable to care for self and need help every day with own needs
Nursing home/assisted living facility resident?
Yes / No
Mobility (from work of Cecile Couchoud, MD, French Renal Epidemiology and Information Network)
I am able to walk without help
I need help to move from a bed to a chair
I am totally unable to get up and move without help
Location of Dialysis Treatment
In-center hemodialysis
Home hemodialysis
Home peritoneal dialysis
Comorbidities
Please say "yes" if you have any of the following illnesses.
Yes / No
Diabetes
Congestive Heart Failure
Heart Attacks or Angina
Peripheral Vascular Disease (problems with circulation in legs)
Stroke
Lung Disease, COPD or Emphysema
Liver Cirrhosis
Cancer
Dementia
Depression
Total Score:
Research team to read to participant and administer the questionnaire:
The next four questions ask about how much anxiety and depression you have. This is a 4-point rating scale with 0 being not at all and 4 being nearly every day.
PHQ-4 Anxiety and Depression
Over the last 2 weeks, how often have you been bothered by the following problems?
Not at All, 0 Several Days, 1 More Than Half of the Days, 2 Nearly Every Day, 3
Feeling nervous, anxious, or on edge

Not being able to stop or control worrying
Anxiety Score
Anxiety is defined as a score of ≥ 3 on the first two questions.
Not at All, 0 Several Days, 1 More Than Half of the Days, 2 Nearly Every Day, 3
Feeling down, depressed, or hopeless
Little interest or pleasure in doing things
Depression is defined as a score of ≥ 3 on the second two questions.
Depression Score
Anxiety and Depression Total Score
Scores of ≥ 3 should prompt treatment.
Patient has scored 3 or more; PI must be notified. Record information about notification in the fields below. Research team will email the Principal Investigator within 24 hours for a score of 3 or more.
Was the PI notified? Yes / No
Date PI was notified
Signature of person completing questionnaire
Research team to read to participant:
The next question is about how well you feel the doctors, nurses and those treating you listen to you.
Heard and Understood
Over the last month, how much have you felt, heard, and understood by the doctors, nurses, and staff who care for you at the dialysis center?
Not at all Slightly Moderately Quite a bit Completely
Research team to read to participant and administer the questionnaire:
Quality of Communication Questionnaire
We would like to know, in as much detail as possible, how good the dialysis team taking care of your medical problems is at talking with you about your illness and the types of care that you would want if you became sicker or too sick to speak for yourself. We know that many people think very highly of the people treating them. To help us improve communication between the treatment team and patients, please be critical.
Using the following scale, where "0" is the worst you could imagine, and "10" is the best you could imagine, please tell me the best number for each statement.
Interviewer: use the last two responses when team did not do...
Turn to the response scale card and read response options
When talking with your dialysis team about important issues like becoming very ill, how good are they at:
0 = The very worst general communication I could imagine 10 = The very best general communication I could imagine Didn't do Don't know
1. Using words that you can understand. 2. Looking you in the eye. 3. Answering all your questions about your illness and treatment.

4. Listening to what you have to say. 5. Caring about you as a person. 6. Giving you his/her full attention.
Score
When talking with your dialysis team about important issues like becoming very ill, how good are they at:
0 = The very worst communication about End-of-Life Care I could imagine 10 = The very best communication about End-of-Life Care I could imagine Didn't do Don't know
7. Talking with you about your feelings concerning the possibility that you might get sicker. 8. Talking with you about the details concerning the possibility that you might get sicker. 9. Talking to you about how long you might have to live. 10. Talking to you about what dying might be like. 11. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself. 12. Asking about the things in life that are important to you. 13. Asking about your spiritual or religious beliefs.
Score
Total Score
Research team to read to participant and administer the questionnaire:
The next three questions ask how well you feel those taking care of you work with you in making decisions. This is a 5-item scale with 0 being no effort was made up to 4 being every effort was made.
CollaboRATE
Thinking about the discussion you have just had with your kidney care team:
0 = No effort was made 1 = A little effort was made 2 = Some effort was made 3 = A lot of effort was made 4 = Every effort was made
How much effort was made to help you understand your health issues?
How much effort was made to listen to the things that matter most to you about your health issues?
How much effort was made to include what matters most to you in choosing what to do next?
Total Score
Research team to read to participant and administer the questionnaire:
The next few questions ask about how important it is to you to talk with those treating you about medical procedures you would and would not want. This is a 5-item scale with 0 being very unimportant and 5 being very important.
Dialysis Patient Preferences and Experiences with End-of-Life Care Discussions
How important is it to have a discussion with a member of your dialysis team about treatment you do and do not want if you become very ill and cannot speak for yourself?
Very Unimportant - 0 points Somewhat Important - 1 point Unsure - 2 points Somewhat Important - 3 points Very Important - 4 points

<p>Yes / No</p> <p>Do you know what supportive (palliative) care* is?</p> <p>Have you had a discussion with a member of your dialysis team about treatment you do and do not want if you become very ill and cannot speak for yourself?</p> <p>During the past 12 months have you had a discussion with your kidney doctor about treatment you do and do not want if you become very ill and cannot speak for yourself?</p> <p>During the past 12 months have you had a discussion with your kidney doctor about your choices for end-of-life care?</p> <p>*Definition of palliative care to read to the patient: Palliative care (pronounced pal-lee-uh-tiv) is special medical care for people who are very ill. This type of care treats pain and symptoms and tries to decrease stress. This care also seeks to find out what matters most to patients to be sure they receive it. The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by specialists who work together with a patient's doctor to provide an extra layer of help. It can be given at any time along with curative treatment.</p>
<p>Research team to read to participant and administer the questionnaire:</p> <p>The next four questions ask about how ready you are to talk to your family and doctor about treatment you would want if you were very sick and if you are ready to fill out papers to put your wishes for treatment in writing. This is a 5-point scale with 1 being I have never thought about it and 5 being I have already done it.</p>
<p>Advance Care Planning Engagement Survey</p>
<p>I have never thought about it - 1 point I have thought about it, but I am not ready to do it - 2 points I am thinking about doing it in the next 6 months – 3 points I am definitely planning to do it in the next 30 days - 4 points I have already done it - 5 points</p> <p>1. How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life? 2. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life? 3. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? 4. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?</p>
<p>Score</p>
<p>Any additional comments or questions:</p>
<p>This concludes the interview. Thank you very much for participating. The \$25 gift card will be mailed to you.</p> <p>**Study team to refer to subject tracker and gift card inventory tracker to complete the process for mailing the gift card. **</p>
<p>Interview End Time:</p>
<p>Interview Length:</p> <p>_____</p> <p>(Time in minutes)</p>

Supplement 6c: KSC-IQ

Dialysis Center Where You Work:

KSC-IQ

This Kidney Supportive Care Implementation Quotient (KSC-IQ) helps nephrology practices, clinics, and dialysis centers examine how they are performing in key areas of implementation of supportive care for seriously ill patients with advanced chronic kidney disease (CKD) or end-stage renal disease (ESRD). If you find areas where your practice could improve, the Pathways Project change package provides tools and guidance for change.

What is supportive care?

Supportive care aims to improve quality of life for patients and family members (as defined by the patient). The term supportive care is used rather than palliative care because that term is preferred by patients and physicians. The terms are synonymous. Kidney supportive care can be provided together with therapies intended to prolong life, such as dialysis, and is offered by the kidney care team throughout the course of kidney disease. When more complex or refractory problems arise, the kidney care team partners with specialist palliative care providers to address these issues. If patients' conditions worsen, they often value comfort more highly and wish to avoid hospitalization. Hospice care then provides coordinated services focused on end-of-life needs.

What does this survey cover?

The survey questions are based on the four sections of the Pathways Project change package. The survey questions ask you how well your practice or clinic is currently doing in the specific supportive care practices. Answer choices are:

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

We encourage you to comment in the provided space on anything your practice does particularly well or on any aspect where your practice needs to improve.

The survey takes a 5-10 minutes to complete. It has 20 questions organized into the four main components of the Pathways Project:

- A. Supportive Care Capacity: Create the System
- B. Values Guide Care: Elicit & Respect Patient Values and Preferences
- C. Just Right Care: The Right Care to the Right Person at the Right Time
- D. Throughout the Continuum: Enhanced Support at the End of Life

A. Supportive Care Capacity: Create the System

1. Our practice has an interdisciplinary team responsible for improving supportive care in our practice. It is clear who is the day-to-day leader(s) of the team responsible for implementing supportive care changes. Appropriate champions (professionals who are opinion leaders in your organization, to whom others go to seek advice and who have the capacity to implement change) provide needed support, resources, and visibility. A plan for improvement with specific supportive care goals is supported by leadership.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

2. Our practice regularly re-assesses our supportive care practices and implements quality improvement projects to improve care in this area.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

3. All staff members have received education in supportive care, including communication skills and symptom management approaches.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

4. Our practice has an established relationship with a community palliative care team and at least one community hospice provider to collaborate in care of nephrology patients with supportive care needs. Relationship may include embedding palliative care team member into nephrology clinic, triggers for referrals to specialty palliative care consultation, palliative care back-up for medical management patients, and other proactive co-delivery of supportive care services that go beyond simple referral.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

B. Values Guide Care: Elicit and Respect Patient Values and Preferences

5. Goals of care conversations: We conduct goals of care conversations with almost all of our patients at least at these points of time: shortly after entering the practice; as education about treatment modes is conducted; as there is evidence of decreasing quality of life (such as repeat hospitalizations, increased symptom burden, caregiver burden, dementia). Staff conducting the conversations follow a best practice format such as the Serious Illness Conversation Guide.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Conversations are documented in chart so that goals of care are easily retrievable by all staff and updated as patient condition or goals change (e.g. NOT buried in visit notes. Should have separate area of chart for goals of care and for advance care plans).

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

6. As part of shared decision making, nephrologists routinely and kindly provide patient-specific prognostic information needed for choosing among treatment options. Nephrologist provides patient and family with information from validated prognostic tool and/or practice-specific outcome statistics relevant to their decision options.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

7. When educating patients about their treatment options, our practice uses evidence-based decision aid(s) that include medical management without dialysis in a balanced and informative way.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in

this area. _____

8. Our practice encourages patients to develop advance care plans. We have forms available. We have a designated staff person who has been trained to conduct these conversations. We have a designated area of medical record to retain copies of advance directives and/or to record patient preferences regarding future care. Our practice routinely completes POLST/MOLST forms for patients who are seriously ill or who have had an unexpected hospitalization.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

C. Just Right Care: The Right Care to the Right Person at the Right Time

9. Our practice routinely screens patients using a standard process such as the "Surprise Question," a frailty score, or another validated prognostic tool to identify appropriate patients for supportive care services.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

10. Our practice has a formal pathway for medical management without dialysis. Our practice has adopted policies, procedures, and standard processes that guide care for patients choosing this pathway. We identify and track patients who have chosen medical management without dialysis. We know the proportion of eligible patients who choose this pathway and the proportion who change their mind and opt for dialysis.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

11. We use a validated/standardized symptom assessment tool that is integrated into regular work flow so that symptom data is collected for most outpatient visits, and at least monthly for dialysis patients.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

12. Using validated tools, our practice routinely assesses psychosocial needs, including depression, caregiver burden, and spiritual concerns.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

13. We have social worker and chaplain available on our interdisciplinary team to help address psychosocial and spiritual needs. We also have working referral relationships to help patients access additional community resources.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

14. We proactively assess and develop plans for seriously ill patients at high risk for ED visits or hospitalization.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

D. Throughout the Continuum: Enhanced Support at End of Life

15. We have relationships with palliative care and/or hospice program that enable rapid transition to these services when patient symptoms escalate. In concert with these services, we are effective in helping patients avoid unwanted ED visits, hospitalizations, and ICU stays. We help patients stay at home with support if that is their goal.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in

this area. _____

16. Our practice is able to provide palliative dialysis to meet patient needs and preferences.

Palliative dialysis is a transition from a conventional disease-oriented focus of dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden in patients predicted to have less than one year to live. With a palliative dialysis approach, a dialysis index > 1.2 does not necessarily need to be met if that goal is inconsistent with the patient's preferences. Additionally, dietary restrictions are reduced, management of hyperphosphatemia and hyperparathyroidism is more permissive, laboratory monitoring is decreased to the bare minimum, dyslipidemia is not treated, hypertension may not be as tightly controlled, and a catheter as dialysis access is acceptable.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

17. Our practice follows best practices in responding to patient requests to discontinue dialysis.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

ABOUT YOU

Thank you for assessing how well your practice provides kidney supportive care. To finish, please answer three questions about your professional role.

18. How many years have you cared for patients with kidney disease, CKD and/or ESRD?

- ☐ Less than one year
- ☐ 1-2 years
- ☐ 3-5 years

- ☐ 6-10 years
- ☐ 11-15 years
- ☐ More than 15 years

19. What is your professional job category?

- ☐ Physician
- ☐ Physician Assistant
- ☐ Nurse Practitioner
- ☐ Nurse
- ☐ Dialysis Technician
- ☐ Dietician
- ☐ Social Worker
- ☐ Administrator
- ☐ Other

If other, please explain: _____

20. Where do you work? (check all that apply)

- ☐ Dialysis center(s)
- ☐ Nephrology outpatient practice or clinic
- ☐ Hospital dialysis unit
- ☐ Palliative care team
- ☐ Hospice
- ☐ Other

If other, please explain: _____

Thank you for taking the time to complete this assessment. It is greatly appreciated.

Supplement 6d: NOMAD adaptation

INSTRUCTIONS

Who should complete this survey:

To be completed by all providers and staff involved in implementing the Pathways Project change package for **dialysis patients**.

Purpose:

This survey is designed to help get a better understanding of how to apply and integrate complex interventions in health care. It is a validated tool that has been designed to capture 16 cognitive and behavioral components related to how new practices become a routine part of work. (To learn more about the survey and for references: <http://www.normalizationprocess.org/nomad-study/>).

How to complete this survey:

This survey asks questions about the implementation of the Pathways Project change package. The “change package” refers to the 14 evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.

This survey is in 3 parts:

Part A asks some brief questions about yourself and your role.

Part B includes general questions about implementing the change package.

Part C contains a set of more detailed questions about your implementation process of 3 components of the change package.

The set of questions in this section are repeated three times because we want to understand how all 16 of the cognitive and behavioral components relate to each of the 3 change package elements separately.

We understand that some people in their roles may work across organizations and with different patient populations; please answer all questions in relation to the **dialysis patient population ONLY for the organization you mark below**.

Please take the time to decide which answer **best suits your experience for each statement and mark the appropriate box**.

PART A: About yourself

1. For which dialysis center do you work?

2. How many years have you worked for that dialysis center?

☐ Less than one year

☐ 1-2 years

☐ 3-5 years

☐ 6-10 years

☐ 11-15 years

☐ More than 15 years

3. What is your profession?

☐ Nurse

☐ Nurse practitioner / physician assistant

☐ Nephrologist

☐ Social worker

☐ Other: _____

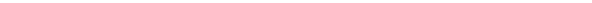
PART B: General questions about implementing the change package

4. Please select which of the 14 elements of the change package you personally have been working to implement so far.

- ☐ Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
- ☐ Assess unmet supportive care needs in patient population
- ☐ Provide education to staff on the principles and practices of primary supportive care, including communication skills
- ☐ Collaborate with palliative care/hospice specialists
- ☐ Implement shared decision-making for current and advance care planning for future care options*
- ☐ Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
- ☐ Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings
- ☐ Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions*
- ☐ Provide medical management without dialysis to patients avoiding or delaying dialysis
- ☐ Screen and manage pain and symptoms
- ☐ Assess psychological and spiritual needs and address needs
- ☐ Proactively identify and manage patients at high-risk for frequent hospital readmission
- ☐ Coordinate care and care transitions with specialty palliative care and hospice
- ☐ Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients*

**indicates core component*

Not at all Somewhat Completely



5. Do you feel identifying seriously ill patients is currently a normal part of your work?

0 1 2 3 4 5 6 7 8 9 10

6. Do you feel identifying seriously ill patients will become or
remain a normal part of your work?

0 1 2 3 4 5 6 7 8 9 10

7. Do you feel advance care planning <u>is currently</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
8. Do you feel advance care planning <u>will become or remain</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
9. Do you feel palliative dialysis <u>is currently</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
10. Do you feel palliative dialysis <u>will become or remain</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10

PART C: Specific questions about change package implementation

The next three sections present detailed statements about the three core components of the change package:

1. identifying and prioritizing seriously ill patients;
2. implementing shared decision making and advance care planning; and
3. palliative dialysis.

Rate how much you agree or disagree with each statement for the component of the change package for that section, or state if it is not relevant.

The set of questions in this section are repeated three times because we want to understand how all 16 of the cognitive and behavioral components of how work becomes normalized relate to each of the 3 change package elements separately.

If you have not yet implemented the element of the change package, skip that set of questions.

Section C1. Please think about your practice of **identifying and prioritizing seriously ill dialysis patients** for this section.

If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how identifying seriously ill patients differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how identifying seriously ill patients affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of identifying seriously ill patients for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive identifying seriously ill patients forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in identifying seriously ill patients is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate identifying seriously ill patients into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that identifying seriously ill patients is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that identifying seriously ill patients has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work with identifying and prioritizing seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C2. Please think about your practice of **shared decision making and advance care planning (ACP)** with dialysis patients for this section.

If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how shared decision making and ACP differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how shared decision making and ACP affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of shared decision making and ACP for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive shared decision making and ACP forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in shared decision making and ACP is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate shared decision making and ACP into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to implement shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that shared decision making and ACP is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that shared decision making and ACP has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C3. Please think about your practice of **palliative dialysis** for this section.
If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how palliative dialysis differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how palliative dialysis affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of palliative dialysis for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive offering palliative dialysis forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in palliative dialysis is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate palliative dialysis into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that palliative dialysis is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that palliative dialysis has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing the survey!

Supplemental Materials

1. Literature search terms and strategy
2. Pathways Project Change Package – 1-page summary
3. Ask-Tell-Ask card
4. Interview guide for interviews of implementation leaders
5. Questions for the Technical Expert Panel meeting
6. Evaluation data collection and survey instruments
 - a. Chart audit instructions
 - b. Patient survey instrument
 - c. KSC-IQ
 - d. NOMAD adaptation

Supplement 1: Search Terms for focused Literature Review

Search Terms for Focused Literature Review:

active medical management without dialysis

bereavement care

chronic kidney disease

chronic kidney failure

chronic renal failure

CKD

communication

comprehensive conservative care

conservative care

conservative kidney management

conservative management

conservative, non-dialytic management

disease, end stage kidney

disease, end stage renal

emergency care

emotional support

end stage kidney disease

end stage renal disease

end stage renal failure

ER

health resource

healthcare resources

hospice

hospice care

hospice program

hospital mortality

hospital readmission

hospitalization

intensive care

kidney disease, end stage

maximal conservative management

morbidity

mortality

non-dialytic management

outcome and process assessment health care

outcomes

pain management

pre ESRD

prognosis

quality of life

renal disease, end stage

renal failure, end stage

renal palliative care

renal supportive care

spiritual support

symptom assessment

symptom management

Supplement 2: Pathways Project Change Package



Pathways Project CHANGE PACKAGE

Evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.



Supportive Care Capacity

Create the System

1. Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
2. Assess unmet supportive care needs in patient population
3. Provide education to staff on the principles and practices of primary supportive care, including communication skills
4. Collaborate with palliative care/hospice specialists



Values Guide Care

Elicit & Respect Patient Values and Preferences

5. Implement shared decision-making for current and advance care planning for future care options **
6. Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
7. Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings



Just Right Care

The Right Care to the Right Person at the Right Time

8. Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions **
9. Provide medical management without dialysis to patients avoiding or delaying dialysis
10. Screen and manage pain and symptoms
11. Assess psychological and spiritual needs and address needs
12. Proactively identify and manage patients at high-risk for frequent hospital readmission



Throughout the Continuum

Enhanced Support at the End of Life

13. Coordinate care and care transitions with specialty palliative care and hospice
14. Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients **

****Indicates a mandatory practice that project participants are required to test and implement**

Supplement 3: Ask-Tell-Ask card



The Ask-Tell-Ask Approach to Conversations
with Seriously Ill Patients with Kidney Disease*
Alvin H. Moss, MD, FACP, FAAHPM

ASK

- **Build trust and strengthen relationship**
 - “I would like to be able to respect your wishes for future medical care. Would it be ok for us to talk about what you would want?”
 - “How are you doing compared to a year ago?”
- **Assess patient/family understanding of the patient’s medical condition and prognosis**
 - “What have physicians told you about your (the patient’s) condition?”
 - “What is your understanding of your (the patient’s) major medical problem now?”
 - “How serious is it?”
- **Determine patient’s goals for treatment in his/her present condition?**
 - “How much information about what is likely to be ahead with your illness would you like from our team?”
 - “What is most important to you in receiving treatment for your illness? What do you hope for?”
 - “What would you want to avoid in receiving treatment for illness (some patients say they would want to avoid being placed on a breathing machine or in a nursing home)? What do you fear?”
- **What are your most important goals if your health situation worsens?**
 - To the health care proxy, “If your _____ (mother, father, etc) was mentally clear and could see what condition he/she is in what would he tell us to do? Are there things he or she would want us to avoid in his/her treatment?”

MEDICARE BILLING CODES FOR ADVANCE CARE PLANNING

99497 16 minutes or longer of first 30 minutes
99498 add on to 99497-includes 30 minutes from 99497 and at least 16 minutes for 99498 for at least 46 minutes of advance care planning

- **Explore understanding of who the patient wants to be his/her healthcare proxy and what the role of the proxy should be.**
 - “Who would you want to make medical decisions for you if you became too sick to make them yourself?”
 - To the patient’s health care proxy, “What do you understand about your role as the healthcare proxy? How are you to make decisions?” (NB: Proxy is to make decisions based upon the patient’s expressed wishes or, if unknown, the patient’s best interest.)

TELL

- **Explain the patient’s overall condition emphasizing the patient’s most serious comorbidities**
- **Discuss likely future complications**
- **Assist with informed decision about breathing machine, ICU, and CPR**
 - “Have you been on a breathing machine before? If you got sick, would you want to be on one again if necessary to keep you alive? To proxy, “Has the patient been on a breathing machine before? Has he/she said anything about wanting/not wanting to be on a breathing machine?”
 - “It is helpful to learn what is most important to you. Would you want—to live as long as possible regardless of pain and suffering or to live a shorter period of time to avoid pain and suffering? (75% of dialysis patients want to live a shorter time to avoid pain and suffering)
 - “Under what circumstances if any would you want to stop dialysis?” (Most patients say if they had a large stroke and were unconscious or if they had severe dementia they would not want to be kept on dialysis)
 - CPR is not as successful as most people think. Would you want those treating you to attempt CPR if your heart stopped? If you live through CPR, you will be on a breathing machine. Is that what you would want?

ASK

- **What questions do you have?**
- **What will you tell your family about what we discussed?**
- **In your own words, please tell me what you understand from our conversation.**

*Reference: Mandel EI, et al. Serious Illness Conversations in ESRD. Clin J Am Soc Nephrol 2017;12:854-863.

Supplement 4: Interview guide for interviews of implementation leaders

Interview guide for discussions with model programs or places with innovative practices

Introduction

- Brief overview of Pathways project – looking for tools, practices, examples for any of the pathways
- Consent to record the interview for purposes of transcribing it.
- Consent to share information about program with Pathways TEP. Further dissemination – we would come back to you for further permission.

Description of the program

- What services are provided?
- Who is served? (get actual numbers served if applicable)
- Staffing?
- Funding?

History

- How did it get started?
- What do you consider the successes to date?
- What have been barriers to success or to implementation?
- How did you overcome barriers (if you did)?

Effectiveness

- How are you measuring effectiveness?
- If formal measurement – what measures being used?
- What data is available on effectiveness? Willing to release any internal data to us?
- Are there any formal studies of the program's impact published? Or underway?
- What data do you have on cost, cost effectiveness, cost savings?

Tools to share

- What are the tools, policies/procedures, educational materials being used?
- Will you share samples? If CSCKP likes the material, are you open to dissemination through Pathways project? (Discussion of attribution, licensing, etc would need to follow.)

Lessons learned

- Lessons learned from developing and using these practices?

Snowball

- Snowball – who else do you know of who is doing useful work in this area?

Supplement 5: Questions for the Technical Expert Panel meeting

TEP – What are we hoping to answer?

1. What are the most effective changes* needed to help CKD patients make an informed and supported choice either for dialysis with integrated supportive care or for comprehensive conservative care?
2. What structure, process and resources are needed to effectively provide comprehensive conservative care for patients who choose it?
3. What are the most effective changes needed to help dialysis patients receive supportive care throughout the kidney care continuum?
4. What are the most effective changes needed to help dialysis patients make an informed and supported choice to discontinue dialysis?
5. Are there certain changes that need to be bundled or sequenced in order to maximally effective?
6. What are the most effective measures to help understand whether changes made are improvements?

*Changes might include:

structure of care

care processes

education for providers, patients, family

clinical tools (such as symptom algorithms or trigger lists for PC consultation)

Supplement 6: Evaluation data collection and survey instruments

- a. Chart audit instructions
- b. Patient survey instrument
- c. KSC-IQ
- d. NOMAD adaptation

Supplement 6a: Chart audit instructions

Instructions for Pathways Follow-Up Chart Audit of Advance Care Planning in Records of Seriously Ill Patients

A follow-up audit of the records of patients who have been identified as seriously ill is to be completed once for each patient by October 5, 2020. The goal is to determine the extent to which information about patient advance care planning goals are documented in the medical record.

A HIPAA full waiver of consent has been obtained from your institution, giving us permission to access the medical records for this purpose. **The information gathered must be de-identified before submitting to Pathways.**

Selecting patient records to audit

Your clinic will be developing a list of patients identified as seriously ill at the beginning of each month. Obtain the lists of patients whom your clinic identified as seriously ill at the beginning of July, August, and September 2020. If conducting this audit at a dialysis center, delete new patients. Specifically, delete any patients who had NOT started dialysis by April 1, 2020.

Searching the EHR

If your clinic has designated a specific place in the chart where advance care planning information is entered, you will search that area first. Record whatever you find in this area as it relates to the data collection items on the spreadsheet. If you do not find the relevant information in that area, you will then search other areas, such as progress notes. Search these areas only back to April 1, 2019. Spend no more than 10 minutes looking up information for each patient. The rationale is that if a provider can't find relevant information about goals of care in 10 minutes, then the information is not in a meaningfully retrievable format. Only information on conversations or documents entered **prior to July 10, 2020** is to be captured.

- First go to area specified for ACP in the chart.
- Then search chart going back no farther than April 1, 2019 and spending no more than 10 minutes per patient, (whichever is less time).
- Only record data for discussions or documents entered into the chart **prior to July 10, 2020**.

Recording the data

- Enter the data into an Excel spreadsheet using the template provided: **"ACP Chart Audit Template.xlsx"**.
- When complete, de-identify the data by removing the MRN and any other identifying information you may have added.
- Save as a de-identified file.

Submitting the data

- Email the spreadsheet using secure email to: pathways_data@gwu.edu OR
- Upload the data to the REDCap project “Pathways”, instrument “Follow-up ACP Chart Audit”.

Definitions

Decision Making Capacity (DMC) Assessed

0=no information recorded about whether DMC assessed

1= clear statement that patient has capacity or not – without any documentation about rationale

2= statement that patient has capacity or not, including documentation of rationale. Expected documentation might include elements such as:

- patient does/does not understand his/her medical condition or
- patient does not remember information provided about his condition earlier in visit or previous visit
- patient is able/not able to weigh the consequences of treatment options
- patient has communicated a choice.

Health care agent/Surrogate named

A surrogate (also called health care proxy, durable power of attorney for health care, medical power of attorney, or health care agent depending on the state) is someone that the patient has named to be able to make medical decisions on the patient’s behalf, if the patient is not able to make decisions for him/herself. For this variable, look for information recorded in the record in an area for surrogate information, on a form for surrogate information used in some states, or in the notes. You do NOT need to look inside an advance care planning form or on POLST/MOLST form.

0=no information recorded whether a surrogate has been named

1= clear statement that patient has declined to name a surrogate

2= statement that patient has named surrogate, but name is not provided (e.g. “sister is surrogate” – but sister’s name not given. The reason this is important is in case where it turns out there are two sisters).

3= Surrogate has been named by patient, name is clearly recorded, but no contact information is recorded.

4 – Name and contact information of surrogate is recorded.

Goals of Care conversation documented

0=no information on goals of care found within 10 minutes of search, or since January 2018.

1= A goals of care conversation is documented, with evidence of the choices selected by patient, but documentation is only from template or checklist.

2= Goals of care conversation is documented, and notes have been personalized to clearly show individual preference. For instance, quotes from patient are included, such as “Patient stated “I’m a fighter, so I would never want to give up.” Or “Patient says “I’ve had a good life, so I’d like to have a gentle end. Just keep me comfortable.”

Date of most recent goals of care conversation or advance care planning conversation

Record month and year of most recent conversation documented. DO NOT RECORD day of the date.

Who conducted most recent GOC or ACP conversation?

Record the person who signed the note of the most recent discussion.

0=unknown

1=nephrologist

2=NP

3=social worker

4=team

5=other

Orders or POLST/MOLST Retrievable in chart

This refers to orders signed by physician or NP, usually using a form for that purpose such as POLST or MOLST. May also include notation of DNR orders or other end of life comfort set orders.

0=absence of any orders such as DNR, POLST, MOLST

1= DNR, POLST, MOLST, LST or other standard end of life order set is in chart

Advance Directive Retrievable in chart

This refers to a form completed by the patient, rather than orders signed by clinician, which is captured above.

0=no evidence patient has completed an advance directive

1= Statement that patient has completed an advance directive, but the document is not accessible in the chart.

2= The advance directive form is retrievable from the chart.

Patient advance directives are in an electronic registry

0= no evidence patient's advance directives or POLST are in a registry accessible to other providers

1= patient's advance directive or POLST has been entered in an electronic registry, such as state registry

Other evidence of ACP

If other evidence of advance care planning found that was not captured by previous questions, record a brief description here.

Optional Notes

Briefly describe any other anomalous or notable information here that was not captured in prior questions.

Supplement 6b: Patient survey instrument

Patient Survey Instrument - English
Record ID
Unique Patient ID
PATIENT CONSENT: IRB approved consent script to be inserted here.
Introduction letter was read to participant? Yes / No
Did patient agree to participate? Patient agreed to participate / Patient did not agree to participate
If patient provided a reason for declining, please specify:
Interview Start Time:
Patient Pre-and Post-Intervention Questionnaire
Research team to read to participant and administer the test:
Patients with kidney disease sometimes have memory problems. The first set of the questions is to test your memory. It should take 5 minutes or less.
MoCA-5 Minute Test
Memory:
Immediate Recall
Face Velvet Church Daisy Red
No / Yes
Score: _____
(/5, 1 point for each word)
Fluency: _____
Number of animals named in 1 minute
Score: _____
(/9, 0.5 point for each animal named)
Fluency Calculated Score:
Orientation
Date Month Year Day Place City
No / Yes
Score: _____
(/6, 1 point for each)
Memory:
Delayed Recall

<p>Face Velvet Church Daisy Red</p>
<p>No / Yes</p>
<p>Score:</p> <p>_____</p> <p>(/10, 2 points for each word recalled)</p>
<p>Total Score:</p> <p>_____</p> <p>(/30)</p>
<p>Next, we will collect your address to mail your gift card. Once this is completed, that will conclude this interview. Thank you for your time!</p>
<p>Notice: Due to the patient scoring below a 23, their responses may not be fully accurate.</p>
<p>Interview terminated / Interview continued</p>
<p>Research team to read to participant and administer the test:</p>
<p>Now I have a few questions about you.</p>
<p>Demographics</p>
<p>Dialysis Center or CKD Clinic:</p>
<p>Gender:</p> <p>Male Female Prefer not to say Other</p>
<p>If other, please explain</p>
<p>Age: (in years)</p>
<p>Ethnicity:</p> <p>Hispanic or Latino Not Hispanic or Latino</p>
<p>Race:</p> <p>American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Prefer not to say Other</p>
<p>If other, please explain</p>
<p>Primary language spoken by patient:</p> <p>English Spanish Chinese Russian Other</p>
<p>If other, please specify</p>
<p>Education: (in years)</p>

Is patient on Medicaid?
Yes / No / Unknown
Address (this will be used to mail the participants gift card)
Years on Dialysis: (in years)
Number of times hospitalized in the last year:
Karnofsky Performance Status Score categories
Do you live alone?
Yes / No
What are you able to do?
<p>Able to carry on normal activity and work</p> <p>Unable to work but able to live at home and care for most personal needs</p> <p>Unable to care for self and need help every day with own needs</p>
Nursing home/assisted living facility resident?
Yes / No
Mobility (from work of Cecile Couchoud, MD, French Renal Epidemiology and Information Network)
<p>I am able to walk without help</p> <p>I need help to move from a bed to a chair</p> <p>I am totally unable to get up and move without help</p>
Location of Dialysis Treatment
<p>In-center hemodialysis</p> <p>Home hemodialysis</p> <p>Home peritoneal dialysis</p>
Comorbidities
Please say "yes" if you have any of the following illnesses.
<p>Yes / No</p> <p>Diabetes</p> <p>Congestive Heart Failure</p> <p>Heart Attacks or Angina</p> <p>Peripheral Vascular Disease (problems with circulation in legs)</p> <p>Stroke</p> <p>Lung Disease, COPD or Emphysema</p> <p>Liver Cirrhosis</p> <p>Cancer</p> <p>Dementia</p> <p>Depression</p>
Total Score:
Research team to read to participant and administer the questionnaire:
<p>The next four questions ask about how much anxiety and depression you have.</p> <p>This is a 4-point rating scale with 0 being not at all and 4 being nearly every day.</p>
PHQ-4 Anxiety and Depression
Over the last 2 weeks, how often have you been bothered by the following problems?
Not at All, 0 Several Days, 1 More Than Half of the Days, 2 Nearly Every Day, 3
Feeling nervous, anxious, or on edge

Not being able to stop or control worrying
Anxiety Score
Anxiety is defined as a score of ≥ 3 on the first two questions.
Not at All, 0 Several Days, 1 More Than Half of the Days, 2 Nearly Every Day, 3
Feeling down, depressed, or hopeless
Little interest or pleasure in doing things
Depression is defined as a score of ≥ 3 on the second two questions.
Depression Score
Anxiety and DepressionTotal Score
Scores of ≥ 3 should prompt treatment.
Patient has scored 3 or more; PI must be notified. Record information about notification in the fields below. Research team will email the Principal Investigator within 24 hours for a score of 3 or more.
Was the PI notified? Yes / No
Date PI was notified
Signature of person completing questionnaire
Research team to read to participant:
The next question is about how well you feel the doctors, nurses and those treating you listen to you.
Heard and Understood
Over the last month, how much have you felt, heard, and understood by the doctors, nurses, and staff who care for you at the dialysis center?
Not at all Slightly Moderately Quite a bit Completely
Research team to read to participant and administer the questionnaire:
Quality of Communication Questionnaire
We would like to know, in as much detail as possible, how good the dialysis team taking care of your medical problems is at talking with you about your illness and the types of care that you would want if you became sicker or too sick to speak for yourself. We know that many people think very highly of the people treating them. To help us improve communication between the treatment team and patients, please be critical.
Using the following scale, where "0" is the worst you could imagine, and "10" is the best you could imagine, please tell me the best number for each statement.
Interviewer: use the last two responses when team did not do...
Turn to the response scale card and read response options
When talking with your dialysis team about important issues like becoming very ill, how good are they at:
0 = The very worst general communication I could imagine 10 = The very best general communication I could imagine Didn't do Don't know
1. Using words that you can understand. 2. Looking you in the eye. 3. Answering all your questions about your illness and treatment.

4. Listening to what you have to say. 5. Caring about you as a person. 6. Giving you his/her full attention.
Score
When talking with your dialysis team about important issues like becoming very ill, how good are they at:
0 = The very worst communication about End-of-Life Care I could imagine 10 = The very best communication about End-of-Life Care I could imagine Didn't do Don't know
7. Talking with you about your feelings concerning the possibility that you might get sicker. 8. Talking with you about the details concerning the possibility that you might get sicker. 9. Talking to you about how long you might have to live. 10. Talking to you about what dying might be like. 11. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself. 12. Asking about the things in life that are important to you. 13. Asking about your spiritual or religious beliefs.
Score
Total Score
Research team to read to participant and administer the questionnaire:
The next three questions ask how well you feel those taking care of you work with you in making decisions. This is a 5-item scale with 0 being no effort was made up to 4 being every effort was made.
CollaboRATE
Thinking about the discussion you have just had with your kidney care team:
0 = No effort was made 1 = A little effort was made 2 = Some effort was made 3 = A lot of effort was made 4 = Every effort was made
How much effort was made to help you understand your health issues?
How much effort was made to listen to the things that matter most to you about your health issues?
How much effort was made to include what matters most to you in choosing what to do next?
Total Score
Research team to read to participant and administer the questionnaire:
The next few questions ask about how important it is to you to talk with those treating you about medical procedures you would and would not want. This is a 5-item scale with 0 being very unimportant and 5 being very important.
Dialysis Patient Preferences and Experiences with End-of-Life Care Discussions
How important is it to have a discussion with a member of your dialysis team about treatment you do and do not want if you become very ill and cannot speak for yourself?
Very Unimportant - 0 points Somewhat Important - 1 point Unsure - 2 points Somewhat Important - 3 points Very Important - 4 points

<p>Yes / No</p> <p>Do you know what supportive (palliative) care* is?</p> <p>Have you had a discussion with a member of your dialysis team about treatment you do and do not want if you become very ill and cannot speak for yourself?</p> <p>During the past 12 months have you had a discussion with your kidney doctor about treatment you do and do not want if you become very ill and cannot speak for yourself?</p> <p>During the past 12 months have you had a discussion with your kidney doctor about your choices for end-of-life care?</p> <p>*Definition of palliative care to read to the patient: Palliative care (pronounced pal-lee-uh-tiv) is special medical care for people who are very ill. This type of care treats pain and symptoms and tries to decrease stress. This care also seeks to find out what matters most to patients to be sure they receive it. The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by specialists who work together with a patient's doctor to provide an extra layer of help. It can be given at any time along with curative treatment.</p>
<p>Research team to read to participant and administer the questionnaire:</p> <p>The next four questions ask about how ready you are to talk to your family and doctor about treatment you would want if you were very sick and if you are ready to fill out papers to put your wishes for treatment in writing. This is a 5-point scale with 1 being I have never thought about it and 5 being I have already done it.</p>
<p>Advance Care Planning Engagement Survey</p> <p>I have never thought about it - 1 point I have thought about it, but I am not ready to do it - 2 points I am thinking about doing it in the next 6 months – 3 points I am definitely planning to do it in the next 30 days - 4 points I have already done it - 5 points</p> <p>1. How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life? 2. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life? 3. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? 4. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?</p>
<p>Score</p>
<p>Any additional comments or questions:</p>
<p>This concludes the interview. Thank you very much for participating. The \$25 gift card will be mailed to you.</p> <p>**Study team to refer to subject tracker and gift card inventory tracker to complete the process for mailing the gift card. **</p>
<p>Interview End Time:</p>
<p>Interview Length:</p> <p>_____</p> <p>(Time in minutes)</p>

Supplement 6c: KSC-IQ

Dialysis Center Where You Work:

KSC-IQ

This Kidney Supportive Care Implementation Quotient (KSC-IQ) helps nephrology practices, clinics, and dialysis centers examine how they are performing in key areas of implementation of supportive care for seriously ill patients with advanced chronic kidney disease (CKD) or end-stage renal disease (ESRD). If you find areas where your practice could improve, the Pathways Project change package provides tools and guidance for change.

What is supportive care?

Supportive care aims to improve quality of life for patients and family members (as defined by the patient). The term supportive care is used rather than palliative care because that term is preferred by patients and physicians. The terms are synonymous. Kidney supportive care can be provided together with therapies intended to prolong life, such as dialysis, and is offered by the kidney care team throughout the course of kidney disease. When more complex or refractory problems arise, the kidney care team partners with specialist palliative care providers to address these issues. If patients' conditions worsen, they often value comfort more highly and wish to avoid hospitalization. Hospice care then provides coordinated services focused on end-of-life needs.

What does this survey cover?

The survey questions are based on the four sections of the Pathways Project change package. The survey questions ask you how well your practice or clinic is currently doing in the specific supportive care practices. Answer choices are:

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

We encourage you to comment in the provided space on anything your practice does particularly well or on any aspect where your practice needs to improve.

The survey takes a 5-10 minutes to complete. It has 20 questions organized into the four main components of the Pathways Project:

- A. Supportive Care Capacity: Create the System
- B. Values Guide Care: Elicit & Respect Patient Values and Preferences
- C. Just Right Care: The Right Care to the Right Person at the Right Time
- D. Throughout the Continuum: Enhanced Support at the End of Life

A. Supportive Care Capacity: Create the System

1. Our practice has an interdisciplinary team responsible for improving supportive care in our practice. It is clear who is the day-to-day leader(s) of the team responsible for implementing supportive care changes. Appropriate champions (professionals who are opinion leaders in your organization, to whom others go to seek advice and who have the capacity to implement change) provide needed support, resources, and visibility. A plan for improvement with specific supportive care goals is supported by leadership.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

2. Our practice regularly re-assesses our supportive care practices and implements quality improvement projects to improve care in this area.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

3. All staff members have received education in supportive care, including communication skills and symptom management approaches.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

4. Our practice has an established relationship with a community palliative care team and at least one community hospice provider to collaborate in care of nephrology patients with supportive care needs. Relationship may include embedding palliative care team member into nephrology clinic, triggers for referrals to specialty palliative care consultation, palliative care back-up for medical management patients, and other proactive co-delivery of supportive care services that go beyond simple referral.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

B. Values Guide Care: Elicit and Respect Patient Values and Preferences

5. Goals of care conversations: We conduct goals of care conversations with almost all of our patients at least at these points of time: shortly after entering the practice; as education about treatment modes is conducted; as there is evidence of decreasing quality of life (such as repeat hospitalizations, increased symptom burden, caregiver burden, dementia). Staff conducting the conversations follow a best practice format such as the Serious Illness Conversation Guide.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Conversations are documented in chart so that goals of care are easily retrievable by all staff and updated as patient condition or goals change (e.g. NOT buried in visit notes. Should have separate area of chart for goals of care and for advance care plans).

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

6. As part of shared decision making, nephrologists routinely and kindly provide patient-specific prognostic information needed for choosing among treatment options. Nephrologist provides patient and family with information from validated prognostic tool and/or practice-specific outcome statistics relevant to their decision options.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

7. When educating patients about their treatment options, our practice uses evidence-based decision aid(s) that include medical management without dialysis in a balanced and informative way.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in

this area. _____

8. Our practice encourages patients to develop advance care plans. We have forms available. We have a designated staff person who has been trained to conduct these conversations. We have a designated area of medical record to retain copies of advance directives and/or to record patient preferences regarding future care. Our practice routinely completes POLST/MOLST forms for patients who are seriously ill or who have had an unexpected hospitalization.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

C. Just Right Care: The Right Care to the Right Person at the Right Time

9. Our practice routinely screens patients using a standard process such as the "Surprise Question," a frailty score, or another validated prognostic tool to identify appropriate patients for supportive care services.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

10. Our practice has a formal pathway for medical management without dialysis. Our practice has adopted policies, procedures, and standard processes that guide care for patients choosing this pathway. We identify and track patients who have chosen medical management without dialysis. We know the proportion of eligible patients who choose this pathway and the proportion who change their mind and opt for dialysis.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

11. We use a validated/standardized symptom assessment tool that is integrated into regular work flow so that symptom data is collected for most outpatient visits, and at least monthly for dialysis patients.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

12. Using validated tools, our practice routinely assesses psychosocial needs, including depression, caregiver burden, and spiritual concerns.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

13. We have social worker and chaplain available on our interdisciplinary team to help address psychosocial and spiritual needs. We also have working referral relationships to help patients access additional community resources.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

14. We proactively assess and develop plans for seriously ill patients at high risk for ED visits or hospitalization.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

D. Throughout the Continuum: Enhanced Support at End of Life

15. We have relationships with palliative care and/or hospice program that enable rapid transition to these services when patient symptoms escalate. In concert with these services, we are effective in helping patients avoid unwanted ED visits, hospitalizations, and ICU stays. We help patients stay at home with support if that is their goal.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in

this area. _____

16. Our practice is able to provide palliative dialysis to meet patient needs and preferences.

Palliative dialysis is a transition from a conventional disease-oriented focus of dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden in patients predicted to have less than one year to live. With a palliative dialysis approach, a dialysis index > 1.2 does not necessarily need to be met if that goal is inconsistent with the patient's preferences. Additionally, dietary restrictions are reduced, management of hyperphosphatemia and hyperparathyroidism is more permissive, laboratory monitoring is decreased to the bare minimum, dyslipidemia is not treated, hypertension may not be as tightly controlled, and a catheter as dialysis access is acceptable.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

17. Our practice follows best practices in responding to patient requests to discontinue dialysis.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

ABOUT YOU

Thank you for assessing how well your practice provides kidney supportive care. To finish, please answer three questions about your professional role.

18. How many years have you cared for patients with kidney disease, CKD and/or ESRD?

- ☐ Less than one year
- ☐ 1-2 years
- ☐ 3-5 years

- ☐ 6-10 years
- ☐ 11-15 years
- ☐ More than 15 years

19. What is your professional job category?

- ☐ Physician
- ☐ Physician Assistant
- ☐ Nurse Practitioner
- ☐ Nurse
- ☐ Dialysis Technician
- ☐ Dietician
- ☐ Social Worker
- ☐ Administrator
- ☐ Other

If other, please explain: _____

20. Where do you work? (check all that apply)

- ☐ Dialysis center(s)
- ☐ Nephrology outpatient practice or clinic
- ☐ Hospital dialysis unit
- ☐ Palliative care team
- ☐ Hospice
- ☐ Other

If other, please explain: _____

Thank you for taking the time to complete this assessment. It is greatly appreciated.

Supplement 6d: NOMAD adaptation

INSTRUCTIONS

Who should complete this survey:

To be completed by all providers and staff involved in implementing the Pathways Project change package for **dialysis patients**.

Purpose:

This survey is designed to help get a better understanding of how to apply and integrate complex interventions in health care. It is a validated tool that has been designed to capture 16 cognitive and behavioral components related to how new practices become a routine part of work. (To learn more about the survey and for references: <http://www.normalizationprocess.org/nomad-study/>).

How to complete this survey:

This survey asks questions about the implementation of the Pathways Project change package. The “change package” refers to the 14 evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.

This survey is in 3 parts:

Part A asks some brief questions about yourself and your role.

Part B includes general questions about implementing the change package.

Part C contains a set of more detailed questions about your implementation process of 3 components of the change package.

The set of questions in this section are repeated three times because we want to understand how all 16 of the cognitive and behavioral components relate to each of the 3 change package elements separately.

We understand that some people in their roles may work across organizations and with different patient populations; please answer all questions in relation to the **dialysis patient population ONLY for the organization you mark below**.

Please take the time to decide which answer **best suits your experience for each statement and mark the appropriate box**.

PART A: About yourself

1. For which dialysis center do you work?

2. How many years have you worked for that dialysis center?

☐ Less than one year

☐ 1-2 years

☐ 3-5 years

☐ 6-10 years

☐ 11-15 years

☐ More than 15 years

3. What is your profession?

☐ Nurse

☐ Nurse practitioner / physician assistant

☐ Nephrologist

☐ Social worker

☐ Other: _____

PART B: General questions about implementing the change package

4. Please select which of the 14 elements of the change package you personally have been working to implement so far.

- ☐ Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
- ☐ Assess unmet supportive care needs in patient population
- ☐ Provide education to staff on the principles and practices of primary supportive care, including communication skills
- ☐ Collaborate with palliative care/hospice specialists
- ☐ Implement shared decision-making for current and advance care planning for future care options*
- ☐ Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
- ☐ Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings
- ☐ Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions*
- ☐ Provide medical management without dialysis to patients avoiding or delaying dialysis
- ☐ Screen and manage pain and symptoms
- ☐ Assess psychological and spiritual needs and address needs
- ☐ Proactively identify and manage patients at high-risk for frequent hospital readmission
- ☐ Coordinate care and care transitions with specialty palliative care and hospice
- ☐ Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients*

**indicates core component*

Not at all Somewhat Completely

5. Do you feel identifying seriously ill patients is currently a normal part of your work?

0 1 2 3 4 5 6 7 8 9 10

6. Do you feel identifying seriously ill patients will become or
remain a normal part of your work?

0 1 2 3 4 5 6 7 8 9 10

7. Do you feel advance care planning <u>is currently</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
8. Do you feel advance care planning <u>will become or remain</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
9. Do you feel palliative dialysis <u>is currently</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
10. Do you feel palliative dialysis <u>will become or remain</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10

PART C: Specific questions about change package implementation

The next three sections present detailed statements about the three core components of the change package:

1. identifying and prioritizing seriously ill patients;
2. implementing shared decision making and advance care planning; and
3. palliative dialysis.

Rate how much you agree or disagree with each statement for the component of the change package for that section, or state if it is not relevant.

The set of questions in this section are repeated three times because we want to understand how all 16 of the cognitive and behavioral components of how work becomes normalized relate to each of the 3 change package elements separately.

If you have not yet implemented the element of the change package, skip that set of questions.

Section C1. Please think about your practice of **identifying and prioritizing seriously ill dialysis patients** for this section.

If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how identifying seriously ill patients differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how identifying seriously ill patients affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of identifying seriously ill patients for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive identifying seriously ill patients forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in identifying seriously ill patients is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate identifying seriously ill patients into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that identifying seriously ill patients is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that identifying seriously ill patients has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work with identifying and prioritizing seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C2. Please think about your practice of **shared decision making and advance care planning (ACP)** with dialysis patients for this section.

If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how shared decision making and ACP differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how shared decision making and ACP affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of shared decision making and ACP for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive shared decision making and ACP forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in shared decision making and ACP is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate shared decision making and ACP into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to implement shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that shared decision making and ACP is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that shared decision making and ACP has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C3. Please think about your practice of **palliative dialysis** for this section.
If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how palliative dialysis differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how palliative dialysis affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of palliative dialysis for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive offering palliative dialysis forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in palliative dialysis is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate palliative dialysis into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that palliative dialysis is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that palliative dialysis has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing the survey!